Caregiving in the First Person for Kidney patients

by

Jenny Underwood

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This book does not give medical treatment professional information. It gives information about a 30 year journey through Kidney Disease

Reference to events have not been researched. The stories are printed as they are told. Some items are repeated and need to be.

Although the editorial staff made every effort to avoid errors and correct them, some were inescapable, including spelling and grammar.

We extend our appreciation to all we have met on our journey who have contributed to this book.

Digital Editor: Jenny Underwood, Editor: Eva Ford Ashford

Facts about Kidney Disease:

- 1 in 3 American adults is at high risk for developing kidney disease today.
- High blood pressure, diabetes, a family history of kidney failure, being over 60, or being from certain populations, such as African Americans or Hispanics, are major risk factors for developing kidney disease.
- 1 in 9 American adults has kidney disease—and most don't know it.
- Early detection and treatment can slow or prevent the progression of kidney disease.

Courage and Hope

The other side of hope is courage. That's when you loved one has to face the myriad of treatments including thrice weekly dialysis treatments.

My son Jamie wrote the following when he was sixteen and only two years into his renal disease. By then he had been on hemodialysis two years, had both his kidneys removed via nephrectomy and had received a kidney transplant. He was one of the kids chosen to receive the Courage Award in the state of Arizona presented by members of the Armed Services who had won a distinguished award for courage.

One Purple Heart recipient said, "These kids face adversity every day while we only had a short period of time in combat. They are to be honored for their courage."

Jamie wrote "Courage is when all your fears kick into high gear! And when it's all over, it is usually followed with overwhelming cheer for those who bear witness to it and most of all for the one who does it."

Hope is what sits in your heart and mind when your loved one is on the roller coaster of renal disease. You hope that they overcome and even flourish in this challenge and the next. There are many points where you hope. When your loved one is in surgery, you hope everything turns out all right. When your loved one is taking a dialysis treatment, you hope that they don't crash (when blood pressure drops rapidly with the rapid takeoff of fluid during dialysis) and if it does happen, that the nurses get there in time to give them normal saline to keep from going into shock.

Hope is what makes you get up every day and deal with what's to come. Hope is what drives you to get a transplant or to get the next best treatment. We kept hope alive and went after four transplants.

Dedication

This is dedicated to Jamie and Michael Underwood

My sons who showed the world what Caregiving in the First Person really means.

Who Should Read This Book?

Challenge: How to deal with Kidney Disease in The First Person

This book deals with kidney disease mainly in the first person. By that I mean I will refer to my patient as my son or Jamie. If it's not him, I will say a patient or the patient in the third person. Our experience is in the first person, lived over thirty years.

Caregiving is a first person activity. Singular first person nouns are "I," "me," "my," "mine" and "we," and first person plural pronouns are "our," "ours," "we" and "us."

First, "End Stage" is not an indication of end of life, it just shows that the kidneys are shutting down, most likely permanently. But without treatment, death occurs. Regardless of the reason, the kidneys cannot filter out toxins and may have limited ability to produce urine. Without treatment, death occurs.

Renal disease may come like a tornado, or it may slowly deteriorate. The symptoms are subtle and may go unnoticed:

- An increase in blood pressure, especially diastolic (B/P = Systolic/Diastolic or 120/80). The diastolic may inch up to 100 while the systolic doesn't get too high.
- Fatigue getting slowly worse.
- Some people learn they have renal failure when they are admitted to the hospital in a coma.
- Some people are very ill with nausea and weakness where others don't show symptoms.

Two Simple Tests to check for Kidney Disease

- Urine Test called ACR. ACR stands for "albumin-to-creatinine ratio." Your urine will be tested for albumin. Albumin is a type of protein. Your body needs protein. But it should be in the blood, not the urine. Having protein in your urine may mean that your kidneys are not filtering your blood well enough. This can be a sign of early kidney disease. If your urine test comes back "positive" for protein, the test should be repeated to confirm the results. Three positive results over three months or more is a sign of kidney

disease.

- Blood Test to estimate your GFR. Your blood will be tested for a waste product called creatinine. Creatinine comes from muscle tissue. When the kidneys are damaged, they have trouble removing creatinine from your blood. Testing for creatinine is only the first step. Next, your creatinine result is used in a math formula with your age, race, and sex to find out your glomerular filtration rate (GFR). Your GFR number tells your health-care provider how well your kidneys are working. Check with your doctor about having a GFR test.

What Can Friends and Family Do?

- With the internet, friends and family can research the disease and learn to watch for critical lab values like creatinine (normal 0.8 to 1.1) and BUN (normal 7-10).
- Friends and family can be critical in making sure that their loved one goes to a doctor and follows orders. Since their loved ones overall health will be impaired, they can listen and give hugs when things aren't going well.
- They can commiserate over the treatment regimens and new life demands. has to do.
- They can provide rides, run errands, and offer to go to medical appointments when needed.
- If the loved one is a candidate for a kidney transplant, they can help find living donors and can even donate a kidney themselves. Social Media has played an important role in finding compassionate transplant donors or donors that do not have a connection to the recipient.

Caregiver Guide: The Caregiver

There are two participants in teaming up for caregiving:

- The helper (or friend or relative who gives support).
- The partner (or person who will dance with you while having renal disease and receiving help).

The two will morph into the heart of a kidney patient team.

When a friend or family gets the diagnosis of ESRD ("End Stage Renal Disease"), it can be frightening because the future is uncertain. Friends and family want to help to the degree possible, some more than others. The audience is just those people, the ones who care enough to put time and effort into under-

standing the new landscape that your loved one is going to travel through and finding ways to help.

The first time you hear about Kidney or Renal disease, you may not know much about the disease or its impact. You may think it means that the person can't urinate or let go of fluids.

The renal function is much more than that. The kidney processes and eliminates toxins and fluids in the body, it controls the release of erythropoietin which makes red blood cells, it releases good enzymes that tell the body what to do, and it does make urine that it deposits in the bladder. The kidneys in conjunction with the heart coordinate the fluid level throughout the body. If either organ is out of sync, a fluid build-up occurs that can damage the body if it isn't controlled.

Early Stage: The Diagnosis

When a person gets the diagnosis that their kidneys are failing, they are probably in a state of shock. This may create a situation where they can't take information in during this critical time. One of the wonders of the internet is that it provides a forum for these people to ask what happens? And what happens next? The diagnosis means in simple terms; their serum creatinine is gradually increasing beyond the 0.8 to 1.2 level that it should, and it is not returning to a normal state. The body becomes unable to clean out toxins. Once chronic renal failure takes over, it starts to increase until action needs to be taken such as going on dialysis or death will occur.

As a friend or relative, you may not be comfortable in talking about urine, elimination and disease processes. Your friend, the kidney person, will also be uncomfortable in the early diagnosis stage, but they will rapidly get over it. They will appreciate every drop of processed urine that comes their way. So, the best way to approach the topic is just to ask about the disease and ask how they feel? Do a bit of research on www.mayoclinic.com or Wikipedia so you can know what to expect.

As a friend, the more you know, the more you can be there to help. You have to respect and maintain the confidentiality of the patient and be guided by what the person wants to share with you.

Who are You?

You may be a friend or relative. You may be in an organization like a church or a club and be an acquaintance. The definition of who you are and who you want to be will determine how involved you get.

You may be able to run errands, provide a ride, or do what the partner needs as a casual helper. Maybe you just need to be there for the conversation that takes the partner away from dwelling on the disease. You may be an emotional helper. You may want to visit the partner in the hospital.

One of my cherished memories was when my son Jamie was in the Hospital after losing his transplanted kidney. It was Thanksgiving day, and things were a bit better from the nephrectomy surgery the day before, meaning there was no evidence of infection. We were happy he lived through it, but we were depressed about going back on dialysis. I had given him the kidney that rejected. We never really talked about our fears. We just tried to get through each day.

Then, Bill and Marie Russell and two other friends showed up at the hospital and took us down to the cafeteria for Thanksgiving lunch. The food was awful. But the love and companionship were so wonderful. I will never, ever forget it.

I remember when family members and friends came to take care of me when I needed a caregiver so I could take care of Jamie, who was still in the hospital. I remember many ways that people called and wanted to hear how things were going to cheer us up when we were fighting the battles to come out alive from the Hospital(s).

In some cases, friends and church members have actually given a kidney to a partner even though they may not be close.

You may want to consider who in your life for whom you are willing to donate an organ. Your children? Your siblings? Your parents? Your friends? Your neighbors? A complete stranger?

You may be a quiet person who waits in the wings for a request for help but not know what to do. That's the majority of people. They may want to help. But the partner has difficulty asking for help. You stay out in the periphery

and observe and don't know whether to get involved or not.

What you are taking on as a caregiver or "How do you say I'm All In as the Primary Helper!"

You are probably related to the partner or be a very close friend to be the primary helper. I became the primary helper because I was the adoptive mother of Jamie, who had been with me for about five years before his kidneys declined. I adopted he and his brother Michael when they were 7 and 9. Jamie's kidneys started deteriorating when he was 13 which is typical for children with kidney disease. When they hit puberty, their growth is too much for their sub-par kidneys. Jamie's brother Michael was all in because of the deep bond and love they had for one another.

So I knew I was in right away. I had no idea of the journey we were taking, but I knew we were with him all the way.

The first time I took him to a hospital for tests, I was completely unprepared as I had never been in a hospital. They took him to a room where they were going to inject him with dye. I was with him dressed in gown and mask. They brought out this huge needle (looked huge to me) and stuck it in his vein. He didn't make a sound, but big tears rolled down his cheeks. I completely lost it. I starting sobbing and wailing. They had to stop the procedure to calm me down. They took me out of the room and tried to continue the procedure. Then a few minutes later, they came back and got me and said Jamie refused to continue until I was there. I composed myself and went in for the rest of the procedure.

Afterward, Jamie asked "Mom, why were you crying?" And I replied "Because I couldn't stand to see you hurt. I wanted to be the one to take your place."

So that day, we made a pact. I would be there for all procedures and hospitalizations possible, and that would be forever.

He told me about being left at the door of the hospital by Foster Parents and how he was in the hospital rooms all the time by himself. He had nobody to fend for him or stay with him. He said he had to watch bad things happen to other kids as well as himself. He would physically fight the hospital staff when they came to do a procedure because he had no other defense.

So I was ALL IN for the rest of his life, and while there were difficulties, there were an amazing number of miracles and rewards, and I never doubted for one minute that this was what I was going to do.

I can't tell you how to decide, but I can tell you it was worth every minute of the journey. It was the most important and far-reaching decision I ever made besides adopting the boys.

No Primary Caregiver

Many partners start out without partners at all. They may be single or have no relatives or friends close who can help. This is very sad and makes the journey very difficult and lonely.

In some cases, the primary caregiver gets scared and abandons the partner, so they have to have the grief and loss of the helper as well as the grief and loss of kidney function.

And in some happy cases, a primary caregiver is acquired along the way. Maybe a friend or church member steps up and takes charge when the partner can't function.

There are kidney and patient organizations in some areas that help.

Secondary Helpers

You may just be a friend or acquaintance. You may be a rest stop on the journey and not part of the long pilgrimage. You have to get past the "How are you doing?" phase and decide "How and what am I doing for this partner?"

One of the first things you can do is ask the primary caregiver to make a list of what they may need help with and keep it with them. The problem with volunteering as a helper is there are no clear tasks to do. So if you can convince the partner or primary helper to maintain a list, it would be very helpful.

By learning about the disease (and especially the diet and restrictions), you can help with caregiving. You can do something simple like haul out the trash or more complicated like visiting in the hospital.

Do you have a choice?

If you are a primary partner or relative, you have to make a choice. You have to decide if you are in. And if you are not, you will pay in regrets for the rest of your life. So the decision to walk away can be as large as the decision to help out.

If you are a friend or acquaintance, you have a choice about the depth of your involvement. You can stand back and wait to be asked for help. Or you can be proactive, get to know the lives the partners are living, and you can help out in a myriad of ways. You can be the one that tells jokes and creates happy times.

Your own life is overcrowded with commitments and activities. You may think you have no time nor energy to help a friend partner with deep needs. You may be afraid to be around sick people.

The truth is, the partner is not contagious and is probably more at risk by being around you than the opposite, especially if the partner has a compromised immune system.

The reward for helping out is immeasurable. You can do a small thing like mail some letters or get supplies. You can bring in an unexpected meal or take a partner to an event that has been out of his/her limits (time, distance, etc). One time we organized a trip to Nevada for a gambling day including hiring a bus. The patients loved it. Another time we helped organize a kidney camp for high school patients.

Do you have a backup?

When you are a primary helper and can't do what is required, it is necessary to have a backup. For example, if the partner has to go to hemodialysis three times a week, they have to get there regardless of the circumstances. They can't miss dialysis. They have it while they are in the hospital and when they travel, but it can't be skipped, or death or hospitalization could be the result.

My son Michael has been my rock for backup. He drove Jamie to dialysis when I was sick. He ran errands. He brought in food. He went to dialysis and sat in the lobby and waited for Jamie for 3+ hours. He came to the hospital. He took care of things at home including the animals. In one summer, he ran our household and business for months at a time. He stayed with Jamie when I had to travel on business.

He had to set aside his own life and goals for Jamie's health. He was glad to do it because he loved his brother so much. He decided as a young child he would be there for Jamie and never wavered in his commitment. It was never easy for Michael because he had learning difficulties. He was diagnosed with Asperger's disease, a form of autism. So what he was needed to do went against what his instincts were. But his love overshadowed all else.

I understand and appreciate how lucky I was not only to have a son Jamie who had kidney disease but to have a second son who committed to be a caregiver. You may not be so lucky.

One of the things I have done is assign myself as backup to a few kidney caregivers. I have gone and spent the night and talked and listened and did what I could to help out. I don't know everything, but I know a lot about kidney disease and how to walk the walk.

How it will impact your life

Partners with kidney disease can impact your life in many, unpredictable ways. If you are primary, you have to arrange your work and family life around the partner. You go to medical appointments and take down information, ask questions, and do research to provide the best care you can. I took care of Jamie in many stages of the disease from in-center hemodialysis to home hemodialysis, from transplants to rejection and in times when his transplant was working but his adherence to medications and treatments were just as important.

I learned so much along the way that I developed a desire to be on the other side of the desk. I wanted to know the information that the medical providers knew. I wanted to exceed what I was doing now. So, I prayed and took some college courses to become a nurse. I thought if I flunked Anatomy and Physiology or Microbiology I would stop. I hated Biology and Chemistry when I was in college. But I found out that I didn't hate it so much anymore. As we covered each disease process, I had lived long enough to know people who had illnesses like the ones we studied. I had also met other kidney partners along the way and knew about the illnesses they had such as diabetes, heart disease and liver disease with renal disease.

I passed the courses and since I already had a degree, had no trouble in being admitted to several nursing schools. This caused another impact on life. When we had to move, we had to figure out what medical facilities were available and how well they were at treating kidney disease. We had to change Doctors and medical providers.

When Jamie was being treated by a Pediatric Urologist in Galveston Hospital at University of Texas Medical Branch, I got a job to move back to Phoenix. His doctor was Dr. Cohen, and he expressed alarm that we were moving away from the treatment he had received at Shriner's Burns Institute and UTMB. He said we had to be careful about where we moved to. He checked out the Phoenix area and identified Dr. Mel Cohen as a pre-eminent pediatric nephrologist so he said we would be in good hands. He knew Jamie was going into years of renal treatment and wanted him to have the best. I didn't understand then at all what would be coming.

Then, we were faced with a move when I was 57 and changing careers. We decided to go home to the Ozarks to my first college. We had checked out the

dialysis facilities by going on vacation there. We knew there were nephrologists and good hospitals who treated renal patients within a couple of hours. He had a series of infections at the facility where he was dialyzing. One would finish, and another would start. We believed this was largely due to the turnover of staff, the changing of equipment where he sat, the staff knowledge, and the reuse of dialyzers. But we had to move to get him to a safe dialysis facility.

We went to DCI Dialysis in West Plains, MO at where he dialyzed for twelve years with excellent results. There was little staff turnover, they adhered strictly to all medical protocols, and they kept him on the same machine with very knowledgeable staff. He did not have one infection. Some of the information on dialysis facilities is now available online at Government site: https://www.medicare.gov/dialysisfacilitycompare/

The primary impacts are the time it takes to ensure the partner gets to all appointments, for hemodialysis this is thrice weekly for 3-4 hours and other appointments including hospitalization. The secondary impacts are those for your own work life. It may curtail travel (although I was able to travel extensively and even internationally by having excellent backup caregivers and nieces, Cyndi and Kamie, who helped) and where you live.

It will impact how you live and what you live for. You will grow and understand medical issues very well and be proactive in treatments.

I don't know if I can do this!

You really don't know how you can do this until you try. There is hope and fear all along the journey.

I have found that the fear is greater the farther away you are to the partner. For example, when Jamie was in the hospital, my fear went up in inverse proportion of how close I was to him. The closer I was, I could deal with the fear. The farther away, my fear would become irrational.

You may have to arrange your life around the rituals of renal disease.

If you are secondary, it won't be as demanding. You can, for the most part, schedule when you help out. You can get into the rhythm of what happens and what is needed. One time my mother, Alice Underwood, came to visit at the hospital and shooed me out of the hospital and bought my lunch at Red Lobster while she stayed with Jamie. It was just the little break I needed to get

my strength back and rejoin the battle.

I'm in - what now?

This will depend on the stage of the disease. In the early stages when dialysis treatment is not imminent, the main focus of the primary caregiver is on getting to appointments, arranging for a renal diet, taking lab tests and watching for signs and symptoms that may indicate a change.

For example, kidney patients are usually anemic, and their blood pressure is high because they can't get rid of enough fluids. You can buy a blood pressure machine and make sure the blood pressure is under control.

For anemia, the Doctor may prescribe EPOGEN which causes the body to create red blood cells, is administered via needle and will require lab tests to see when and how much EPO needs to be given. You have to make sure to make the Doctor and lab visits.

The signs and symptoms of kidney disease are subtle. Some people are asymptomatic until irreversible failure has begun. In children, the only symptom may be high blood pressure. Other patients wind up in a coma in the hospital without ever knowing they had kidney disease. People with diabetes are more prone to kidney disease but may be so focused on their blood/sugar that they miss the kidney symptoms.

Some symptoms to watch for are urine decrease or cessation, increased lethargy, dark circles under the eyes, and a sheen around the face that appears due to uremia.

In our case, Jamie woke up one morning and said "We have to go see the Doctor. There is something wrong with my kidneys."

I took him seriously. We were in Switzerland at the time on a business trip so getting to the doctor was a challenge. But we were back in two days to the news that his creatinine had gone up to 2.0, and we had to watch it carefully, that he was most likely losing his kidneys. There were no time estimates, maybe a year, maybe several years. I have heard there are some steps now that can be made to defer the onset but not back then.

I believe that most people can be primary and secondary caregivers on some level. I have seen caregivers who give so little and create such drama that it's

hard to characterize them as caregivers. I have seen some that are over-protective and counter-protective. By that, I mean caregivers who work and fight against the patient, the providers, and the disease.

I watched one mother of a little girl sneaking glasses of water into her because she was thirsty even though her kidneys were failing and she was on fluid restrictions. I tried to intervene, but she just got mad at me. I have seen others who gave up their lives and careers for caregiving with all the consequences.

Most caregivers are somewhere in between. I have seen writings in medical records where the providers are grading and discussing the caregivers. They characterized me as "Very knowledgeable. Be careful what you say and do." I liked that a lot. There were no sloppy mistakes to be made on my kid.

And the mistakes and aftermath can be dangerous. For example, when a partner has a fistula or graft for dialysis, blood cannot be drawn from the site except by dialysis nurses. Blood pressure can't be taken from that arm as well. So a band needs to on the patient and a sign above the bed saying to leave the fistula alone. The consequences may mean the partner loses a dialysis access requiring the surgical intervention to put in a temporary shunt and build a new fistula or graft.

There are mistakes and the more you know, the more you can deter the mistakes. One day a lunch meal came with a fruit plate of oranges and grapefruit. These contain too much potassium for a kidney patient and could result in heart cessation because failed kidneys do not filter out potassium adequately. The new kidney partner may not understand the danger of high potassium foods (potatoes, tomatoes, watermelon, citrus fruits) which they have been taught are healthy. These need to be substituted with other fruits and vegetables.

One of the main contributions of a primary caregiver is to keep them compliant. There are important fluid restrictions for kidney partners, and they are chronically thirsty. Help by providing ice chips and using small cups and staying away from the 44 ounces and above fast food drinks.

Diet is extremely important and restrictive so don't have food in the kitchen that might cause a kidney partner to eat.

Attitude

When I met Jamie I was struck with how he wanted to live each day of his life without dwelling on his illnesses and medical challenges. He woke up with the attitude that "This day is mine and I will live it!"

Jamie had an exceptional attitude that he would not let kidney disease or dialysis or hospitalizations get in his way of having a normal life. He would keep his hopes and dreams up and keep moving forward. This attitude would splash over to other people. He would not talk about his illness to many people outside the family. He would just get up and go and do what was necessary. Then he would take back his life.

He would get up and go to school. Then he would come home for a nurse to dialyze him for 3-4 hours. He would eat dinner and then go over to a friend's house to play. On non-dialysis days, he would pretend he wasn't sick at all. We would all go along with his attitude because it was infectious and hopeful.

It did him and us no good to be long-faced and worried on days when things

were good. I learned I needed to marshall my strength for the dark days and keep a good, positive attitude on the good days. And trust me, there are many many good days.

This is difficult to do in chronic illnesses like kidney disease. The kidney partner comes off dialysis tired, drained, hungry and with low blood-pressure. Most go home and sleep for the rest of the day. In later years Jamie slept for a few hours but in early years, he got up and went to the next event.

Keeping separate lives

It was very important for us to keep a relatively normal life outside the treatments and hospitalization. We were diligent in finding events and activities outside of the medical life we lived. We would make sure we had activities to do after and between dialysis that would be interesting and important. I remember one patient who took up belly dancing. And a few who never gave up going fishing.

For Jamie, one of his separate life was to read comics. He would follow stories of the characters, and it would take him to other universes and lives outside the ones he had.

When he was in Junior High and High School, he would go to the places that the other kids went and participated in all that he could.

As an adult, he would hang out with friends and be there for them in all sorts of situations. Friends say that they were in awe of him and how he handled his disease.

He would work on his Old Chevy shortbed trucks. He would track down parts and make the trucks run. He made sure he participated in everything he could. When Jamie began dialysis, I had a career in computers.

I held on to my demanding jobs. People would ask how I could continue working. I told them, "When I walk into the door at work, I set all the medical stuff aside and just concentrate on the work inside these walls. Then when I leave, I can concentrate on Jamie and our family needs."

It was a great way to separate our medical from our other lives. When Jamie was taking dialysis at a hospital across from Mesa Community College, I signed up for a writing class that met while he was being dialyzed. I ate

breakfast and went swimming and dwelled on other things while he dialyzed. I always created a separation of the medical from our other life. Jamie demanded it of me.

Having a separate life allowed me to let go for a while. I needed the respite and the challenges of thinking about and reacting to other things.

It may be a simple as taking a walk or going shopping. One day I had an inexplicable and sudden urge for color. I rushed with a friend to a paint and wallpaper store, and we spent several hours looking at color combinations. I believe that was an impulse to get me into another world besides medicine and illness.

We kept all medical equipment, bandages, and medicine out of view in a closet except when we went on home hemodialysis. Then the equipment was everywhere. A semi pulled up and unloaded over fifty boxes of supplies, and the trucks regularly came for delivery. So we arranged our TV Living Room with one spot for dialysis and the other spots for normalcy. We could actually have visitors during dialysis then except for the put on and take off of the machine. We talked to patients who said they did in-center dialysis because they didn't want it invading their home and their life at home.

Many friends who were curious about what we went through visited and saw what it was like. I believe that it helped them to empathize and see what we were doing. It also calmed their worry in a strange way.

When to laugh and when to cry

Well, the laughing part is easy. Laugh all you can. As David Letterman said, "Laugh so hard that snot comes of out your nose." And we did laugh and love more than we probably should have. We would share jokes and stories and good things.

The crying part was not as easy. It would happen for me in the middle of the night. I would try to keep crying at bay during the day. One night I remember crying and praying because it was his birthday and Mother's Day weekend. I begged God for a transplant and to protect my son, and I cried. It was his sixteenth birthday, Guess what? He got a kidney transplant shortly afterward. So we laughed instead of cried.

Laugh often even if things are not funny. Life goes on with kidney failure, and

that's the miracle of the available treatments. Limitations may change your life's directions and plans. But there are many things to laugh at.

One time during a blizzard, we stayed at a motel near dialysis. We could not get the car out so we hitched a ride with a traveler checking in. After dialysis was over, we had no way back to the motel. Taxi's were not running. This guy who was waiting for a family member was sitting in the waiting room being friendly. I asked him if he would take us back. He said he would be glad to.

When Jamie got off dialysis, we got in his car. I told him which direction to go, but he took off in the opposite direction and kept going in circles. It was slick, and the roads were not plowed. I was about to cry, but Jamie smiled.

After we finally talked him into going our directions, we got back to the hotel. We thanked him and went into the lobby. I told Jamie the guy wouldn't listen to what we said. Jamie laughed and said, "Mom, didn't you know he was drunk? Couldn't you smell the alcohol? Why did you get into the car with him."

I had no idea that he was happy and friendly because he was drunk, and it was 9:00 am in the morning! We laughed about it then. So my almost tears turned into smiles, and we were safely back in the hotel. I laughed at many funny things that happened even in medical treatments.

I save my crying and worrying for the middle of the night when I wake up and can't sleep.

We have found we need our rest to meet the needs of the next day and to be ready to laugh at any time.

Keeping energy and optimism going

Optimism is contagious. Energy is the afterburner of optimism. We always played this hand to win. We kept our energy by being compliant, eating largely within the limits but also watching what the body was telling us, and by getting enough rest.

We looked forward to the hours in the day where we could do other activities than dialysis or appointments. We always took along reading material, I brought novels and Jamie read Comics.

He would lose himself in the different superhero characters and their challenges to take himself away from what was happening. He collected thousands of comics through the years and could recite what happened with each character, story and crossover.

He would look forward to getting comics every week. He had subscriptions at comic book stores and would have them saved if we were at the hospital or couldn't pick them up.

It's very important not to get run down while facing this disease. One decision we made was to have dialysis very early in the morning so we would have the rest of the day to do other things. This meant we had to set the alarm and get up at 4:30 am on three mornings to drive thirty minutes and get on the machine in time. We had to go to bed early the night before. We would be chronically short of rest if we didn't get to bed early. We would both either take naps later or go to bed early the next night. We wanted to have control over rest and have the energy to take the next step.

Getting your share of life

You and your loved one have to fight for your share of life. Like no other illness, kidney disease pervades not only your health, but it takes away your time, your dreams, your opportunities, and impacts your future. Going to dialysis or doing home dialysis are not events that can be skipped. Protecting your health with a transplant is paramount and may not allow you to attend events at large crowds, especially with a lot of children or older people.

"Making do" is a term we use in the Ozarks for working with what you have. You survey your life and make choices and take chances on making it the best, even if you don't feel well.

On a typical day on dialysis, after I saw he was connected up, I would read the newspaper, go have breakfast, go swimming, and then shop or run errands until he got off. Then we would make a bee-line for Subway. He would order a Cold-cut Combo and a large coke. That would bring his blood pressure back up 10 to 20 points and keep him from being nauseous. Eating anything else that was greasy or fast food did not have the same effect. Then we would drive home.

I would go on about my work and volunteering. He might nap or read until he

felt better. Then he would get in his truck and go somewhere. He did not stay at home if he could help it. He demanded a life that was as normal as possible.

Not letting worry take over your lives

It's really easy to fall into the what if scenarios with kidney disease. So many things can go wrong. But the worry needs to be pushed aside on good days. There will be enough to go around during hospitalizations and crises.

The worse what if is trying to wish it hadn't happened and that your loved one would return to a normal life without kidney disease. That is still out of reach but the researchers have been making great progress recently to that end.

Did Jamie worry? Of course, but he didn't talk about it much. He kept it to himself because he knew it would impact his brother Michael and me. I would worry and fuss, but he would tamp me down and calm me to focus on what is directly in front of us.

When we were doing home dialysis, the stress was intense to keep the treatments safe. We did it for a year, and it worked well to keep him healthy, but the worry was always there. I would try to take my worry out of our lives but sometimes I couldn't. The last day we dialyzed at home, his tubes started spewing blood everywhere. After we had got it stopped, I broke down and cried. If you think I was strong through these events, you are wrong. He decided right then that we had to go back in center, and we did.

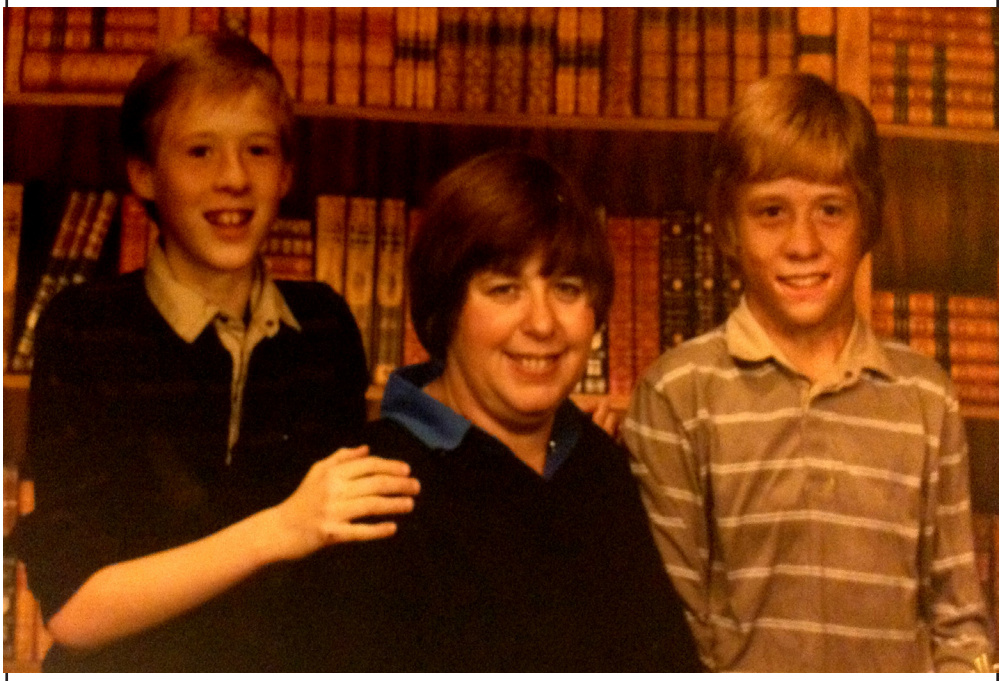
While I tried to keep worry at bay, I could only do it most of the time. Jamie would look into my face and sometimes he would be the calming force for me. The worry never leaves, but it doesn't have to raise its ugly face all the time.

We worried but we kept it to ourselves. We were not a family that talked about bad things to happen. I would look into Jamie's eyes and see hope. One of his friends, a nun at the transplant house said: "When I look into your eyes, I see courage."

I learned to worry and cry in the middle of the night. I worried and paced when he was in surgery. I needed the daytime to be without worry. Kidney disease was treatable. New treatments were being researched. I followed the

development of the pig kidney and the wearable artificial kidney.

Jamie had been fortunate to experience "Just In Time" medicine for his entire life. When he needed the treatment, it was there for him. I would worry that we wouldn't get to treatment in time and that he would crash or that I wouldn't know how to care for him, or his providers wouldn't know what to do.



We had faith that God knew what to do. So many times we left it up to him. And we got several miracles as a result.

But I found that worry was draining. My brother, Larry Underwood, who was dying of cancer told me, "Would you and Mom quit looking at me with long worried faces?"

So, instead, we took him to a restaurant and laughingly ordered a dessert called "Death by Chocolate."

Anybody can look at my overweight status and know that I stuffed myself when worry got too much or even when I was high on happiness. It was my

coping mechanism.

Hope and Courage

Hope and courage are what you need to focus on. Hope for a transplant. Courage to face another day without feeling the best. Courage to stay compliant and not give up. Courage to show others how to have courage.

Jamie said one day, "I don't know why I am still alive when I've been through so much. I guess it is to give other people hope and courage."

Hope is what sits in your heart and mind when your loved one is on the roller coaster of renal disease. You hope that they overcome and even flourish in this challenge and the next. There are many points where you hope. When your loved one is in surgery, you hope everything turns out alright. When your loved one is taking a dialysis treatment, you hope that they don't crash (when blood pressure drops rapidly with the rapid takeoff of fluid during dialysis) and if it does happen, that the nurses get there in time to give them normal saline to keep from going into shock.

Hope is what makes you get up every day and deal with what's to come. Hope is what drives you to get a transplant or to get the next best treatment. We kept hope alive and went after four transplants.

Playing to Win

Challenge: Being a Winner

My mother, Alice Underwood Nix, loved to go to Lake Tahoe and for some time, loved to go to horse races and bet. She won more than she should have and enjoyed these trips until she passed. When she flew in to help one time when Jamie almost died, she looked at me and said, "There's only one way to play this, play to win."

I can't stress how right-on she was. Jamie liked to go to the Casinos on the reservations when they started in Arizona, and he was a winner more times than not. However, I was better if I just read a book while they gambled because I lost at every game I tried.

We have seen patients get the diagnosis of End Stage Renal Failure who give up almost immediately, and they tend to die sooner. They are overwhelmed by the treatments and restrictions.

Jamie would try to influence these patients who were newly on dialysis by talking to them about how to cope with the disease. I would talk to their family members in the lobby, maybe take them to breakfast. I would talk about the highs and wins and how it is not a death sentence.

Working with the team

There are many teams that worked for us. All were important at different times.

The Home Team

We were devoted to Jamie and his challenges. Nothing was more important than making sure he had the chance to do well and get well if possible. For renal disease, that meant going to dialysis, being compliant and living life as it came. When he got transplants, it meant taking care of his kidney and avoiding rejection.

We learned everything we could and did everything we could to take care of him. Some people are not lucky enough to have this home team. Some people even get shunned by family members who don't understand what is going on. But we were lucky in the commitments we made and the love we shared.

The friends team

Not only the patient but the caregiver needs a friends team. You need to be able to visit other people and do things with friends apart from the medical events.

I had friends I called on when the car broke down, and we needed a ride to dialysis. I had friends that gardened with me and played Bridge with me. I had friends that I could unload on and others that would take me away from whatever would happen. I cherish our friends and their willingness to go with us on this journey.

The medical team

The medical team is important sporadically and when needed but they don't need to dominate your life. Don't get me wrong, we had excellent medical care and had very few complaints. We had teams that went to the wall for us. And teams that saved Jamie's life.

We had teams, especially on dialysis, that were like family. We had a nurse that loved Jamie so much that she quit her job at a dialysis facility and took a job on home dialysis so she could take care of him. She was the nurse who put his dialysis needles in for the first time when he was only fourteen. He cried, and she cried.

She looked at him and said, "I can't do this without you. Please help me or you have to go back to the hospital." And he let her do it.

We've had teams that teased him and made him laugh. They always liked him because he was so brave and personable.

I've read excerpts of medical records when he was a baby, and he was not so nice. He cried and screamed and bit all of the medical people who came near him. They asked for a psychiatric consult and the psychiatrist said, "Well, he bites everybody, not just one or two. This is an understandable reaction given that most everything hurts. He is a fighter will survive because of it."

You have the right to take issue and change medical team members. We fired a Doctor once who would not come into the room after having Jamie get completely undressed. We could hear him talking to his stock broker while Jamie sat there freezing. After an hour, we walked off and never returned.

The prayer team

This is the team that you may not know about but is there in the dark days. When Jamie would be in a critical situation in the hospital, I would call everyone I could think of who went to church and asked the church to pray for him, and they did. I would hear later about how hard they prayed.

After Jamie had got his last transplant, we had churches all over our area and the country praying for him. After we had got back, we went around and visited all the churches to thank them for their prayers.

We also attended prayer services in the cities where we were getting treated. I remember a fantastic Catholic Church service on the grounds of Mayo Clinic

in Rochester, Minnesota where we attended service several times.

And when we were in the hospital, I always went to the chapel. One time I went down to pray on a Wednesday and all of a sudden a whole bunch of people came in and surrounded me until I couldn't get away. A priest conducted an Ash Wednesday service, and I got my forehead blessed with ashes. When I got back to the hospital room and Jamie asked, "What's that dirt on your forehead?"

I answered, "You would never believe it, but …."

What Can Friends and Family Do?

The most important thing they can do is to be there for aspects of their lives, not just medical events. Be there both in person and in thoughts and in prayer.

Help your friend. Play to Win.

Medical training you need

The primary training will come from observation and by doing internet searches. When the diagnosis of ESRD first comes, you are in shock and your inputs are not open. After about six months you are ready to learn.

We joined a kidney patient organization in Phoenix, AZ called AAKP which had seminars and events for kidney patients. The Arizona Kidney Foundation was also helpful in training and events. We would come up with ideas of what we would want to learn.

The dialysis centers are usually too busy to do much training but the transplant centers are excellent at teaching. By the time you are ready for transplant, you usually have gotten the hang of End Stage Renal Disease and ready to move on to the big time.

Hospital libraries and online search services are good resources. I have spent many hours reading the journals and studies.

Many caregivers step up to be dialysis providers in a home setting and some even go on to work at dialysis centers.

Lab values

Labs are done often. The two labs to watch for are Serum Creatinine and BUN to see if the kidneys or dialysis is working. These values determine the stages of kidney disease. An early indicator of renal disease is protein in the urine which occurs more than once.

Creatinine is a waste product excreted by muscles into the bloodstream and passed out through urine. A high level in the blood says it isn't being cleaned out. Normal creatinine is between 0.9 to 1.2. Once it reaches 3.0, renal disease is irreversible. In an acute situation where the creatinine goes up to a high level fast (like in a day), it may be reversible. But if the rises gradually, it signifies the march toward kidney failure.

BUN is Blood Urea Nitrogen which is a normal waste product from breakdown of protein from foods you eat. It is normally removed from your blood by your kidneys, but when kidney function slows down, the BUN level rises. BUN can also rise if you eat more protein, and it can fall if you eat less protein.

There are other blood chemistries that may indicate problems where adjustments need to be made. Diabetes and heart patients have other lab values they need to track.

Hematocrit is a measure of red blood cells made by your body. A low hematocrit can mean you have anemia and need to be treated with EPO which is made synthetically. Hematocrit needs to be at least 33 to 36 percent. The kidneys secrete three hormones.

- Erythropoietin (eh-RITH-ro-POY-eh-tin), or EPO, which stimulates the bone marrow to make red blood cells
- Renin (REE-nin), which regulates blood pressure
- Calcitriol (kal-suh-TRY-ul), the active form of vitamin D, which helps maintain calcium for bones and for normal chemical balance in the body

Iron levels may be low and need to be augmented to help build red blood cells. Some patients have high Parathyroid Hormone (PTH) which may result from a poor balance of calcium and phosphorus which can cause bone disease.

Potassium is a mineral in your blood that helps your heart and muscles work properly. A potassium level that is too high or too low may weaken muscles and change your heartbeat. If your kidneys aren't working, your potassium goes up if not limited in diet or dialyzed out. Whether you need to change the amount of high-potassium foods in your diet depends on your stage of kidney disease. Ask your doctor what your potassium level should be.

When on dialysis, these ranges are significantly higher than normal and vary wildly between and after dialysis sessions.

The American Kidney Fund has a Kidney Patient Health Tracker at http://www.kidneyfund.org/kidney-problems/brochures/brochure-pdf/kidney-health-tracker-may-2015.pdf

Signs and symptoms of trouble

Anytime a kidney patient gets sick is a cause for concern. Kidney patients with heart disease and diabetes are of particular concern because they are more fragile.

Because dialysis is in a community outpatient setting, more diseases are community acquired. But because hemodialysis cleanses the bloods, some diseases like influenza are less common. Infections or collapse of the access port are particularly troublesome.

Anything out of the ordinary needs to be reported to your nephrologist or your family doctor.

Hospitalizations are more common than in the general population so get prepared to know your hospital well.

If you have a transplant, you may need to go back to the transplant center for visits and hospitalization.

What to do while waiting

You will spend lots of time waiting as a caregiver. Hemodialysis is 3-4 hours three times a week, and if you accompany your patient there, you will have time to waste. The obvious choices are reading and watching TV, but that gets old really fast.

Some caregivers don't go to dialysis but I always did unless I was sick. I was always worried about Jamie having to go to the hospital from treatment and me no available. It didn't happen often but it did happen a few times. Twice he had to be transported by Medical Helicopter to the nearest large hospital.

Some people sleep in their cars. Most go out to eat or shop. I went swimming, attended events and classes, and visited. Once I worked on community gardens close to dialysis.

Peritoneal dialysis is done at home or in a center at night while a patient sleeps. Patients may need help with supplies or even to visit to pass the time during the day.

The wait isn't as structured for transplant, but it can involve large amounts of hospital time. I learned to walk my rounds every day visited several floors, the chapel, and I especially enjoyed visiting the newborn unit to see the babies. I would also walk the perimeter once or twice just to get outside for a bit. I would sneak in attend classes I saw posted.

Getting Paid

Most of the time, caregiving is voluntary and for free. But some states and areas allow family members and/or friends to be paid for caregiving. For example, the VA has some funding that allows chores to be done on behalf of veterans.

Mileage for driving to treatments may be reimbursed.

Renal Patient Options

Once your creatinine and BUN get too high, you will need to get your kidney boosted by getting dialysis. You have no choice but to get treated, or you will die which is also a choice. You can be put on a transplant list and hope to get a kidney, but it may not happen before you need to go on dialysis.

There are several renal patient options. The choices made at the start of dialysis may be changed to other types over time. For example, if a patient selects peritoneal dialysis and gets an infection, they may switch to hemodialysis until the problems are solved. Some patients get on hemodialysis, then get a transplant, and, unfortunately, may go back on hemodialysis after the trans-

plant fails.

The primary choices

- Hemodialysis where your blood is pumped through a machine and filtered. This requires a port inserted into your chest or the building of an access, either a fistula or graft. It is done either at a dialysis center three times per week or at home for up to five times per week.
- Peritoneal dialysis where fluids are filtered through the peritoneal lining in the abdomen. This requires a port into the abdomen. This dialysis is done multiple times per day or overnight and occurs at home.
- Transplantation where your kidney is replaced by a donor's kidney. If you have a person who can donate a kidney and is a match, you can go ahead with the surgery without going on dialysis. If the kidney doesn't match, you can potentially go on a paired donation chain and exchange your donor for one that matches and get the transplant.

Several web sites offer charts and comparisons: http://www.homedialysis.org/documents/ModalityComparison.pdf shows the pros and cons of home dialysis.

One chart directs your choices based on life style:
http://mydialysischoice.org/

One of the choices shows how getting a transplant may be impacted by the choice of dialysis treatment types. One of the goals is to stay out of the hospital as much as possible and shows the average days in the hospital a renal patient has. Survival rates over 5 years are also shown by type of dialysis. Transplants offer the best long term survival and opportunity to lead a normal life.

A Comparison Chart of Dialysis Types is downloadable at http://www.homedialysis.org/documents/ModalityComparison.pdf

Hemodialysis is performed by initially using a port that has been inserted into a vein so blood can be exchanged in a dialyzer. Later on, a permanent access is built in the arm or leg so that blood can be exchanged via needles. Most hemodialysis is performed in an outpatient center by nursing staff.

Home hemodialysis is performed by a trained (family or friend) support person. Some areas have home dialysis if there is a family member to perform the treatment after training. Home hemodialysis is performed more days and

more hours than in-center and may result in better elimination of toxins and fluid buildup. Friends can visit while dialysis is occuring except at the beginning and end of treatment.

Our friends, Daniel and Keith Thorpe were frequent visitors as was the Hegedis Family: Joe, Violet, Josip, and Suzanna

Home hemodialysis can also be performed at night while you sleep called noctural home hemodialysis. You are hooked up to a machine which will alarm and wake you up if anything is wrong. You can also get nocturnal in-center dialysis at some clinics which doesn't require a home trained caregiver. So basically, you drive to a dialysis center and sleep there six nights a week. But in all cases of home hemodialysis, the more dialysis is performed, the better your blood is cleansed.

Peritoneal dialysis is usually performed at home by a patient and may not require a caregiver. A port access is surgically inserted into the peritoneum lining. After it has healed, dialysis solutions are either pumped or by gravity drained into the peritoneum cavity and then drained or pumped out. This happens several times a day for the gravity system called CAPD. CCPD/APD can be performed at night with a pump as you sleep.

Peritoneal dialysis has less costs to the patient because it eliminates the need for travel except for training and checkouts. It's also beneficial in that the diet is not as restrictive.

Home dialysis requires storage space for supplies. We can recall the day the semi tractor trailer truck pulled up in our driveway and unloaded over 50 boxes to our extra bedroom. After the first delivery, then the patient is required to order supplies to be delivered as needed.

Finding a home dialysis center for training can be tricky. Here is a site to help: http://www.homedialysis.org/life-at-home/articles/how-to-find-a-home-dialysis-center

Since you only drive once a month, you can live a further distance from the center that if you do in-center hemodialysis. There are maps at the above location showing the coverage of areas for home dialysis.

Financial Topics

Challenge: How to Pay for Treatments

The treatment for kidney disease is very expensive and would torpedo almost any patient's ability to pay. The good news is that Medicare pays for ESRD ("End Stage Renal Disease") regardless of age because it is so expensive.

Due to the courage of one patient, Lou Sands, treatments are available regardless of age or insurance status. In the early days of dialysis treatment, there were limited machines. Death panels were used to determine who would get treatment and who would die. Lou Sands took it upon himself and all kidney patients to show Congress what it was like. He brought his machine and nurse to the floor of Congress and dialyzed in front of them when the bill was being debated. Congress passed a resolution that said these patients would get access to treatment via Medicare regardless of age as long as they met certain guidelines. The result was that dialysis centers were built and staffed. The treatment was lifesaving and improves with time and research. They also approved transplantation when it became available. Transplantation is comparatively cheaper in the long run, but organs are in short supply.

When my son Jamie started on dialysis, we had private insurance and applied for Medicare. We started being bombarded with bills from the hospital for the removal of his kidneys and placement of stents and from the in and out patient dialysis. I asked his Pediatric Nephrologist, Dr. Mel Cohen (now deceased), what were we going to do?

He said, "Well, you are going to take care of him, aren't you?"
I replied, "Of course I am."

He took a stack of papers from his desk and threw them in the trash can. He explained, "This is what you are going to do with the bills. Medicare, thank God, is going to take care of most of the big bills."

And we took his words to heart. Medicare performs miracles for End Stage Renal Patients every day, regardless of circumstances. Medicare paid for substantial bills for us through the years. One year we had over $200,000 in

outpatient bills and Medicare paid the bills. I pray that the United States sees the wisdom of single payor and offers Medicare to all of its citizens. We have a model that works and saves lives.

There's no question of the financial impact on care for kidney patients. New expenses include dialysis, medications, treatments, doctors appointments, travel to and from dialysis, special diet restrictions, and increased hospitalization. Most of our bills go into a brown cardboard box where they stay until the medical providers sort out the co-pays and charges.

If a patient is lucky enough to have insurance at the start of dialysis treatment, private insurance pays for the first year, and Medicare is secondary. Then from the second year on, Medicare is primary, and private insurance is secondary. Many dialysis patients aren't able to continue working so they may have to go on Medicaid for the co-pays.

Medicare

Medicare is the primary insurance for ESRD and is a national program. Most US citizens (about 93%) can get Medicare when they start dialysis or have a transplant. To get Medicare, you needed to have worked enough and paid Medicare payroll taxes. If you haven't worked enough, you can get Medicare under a spouse's work record. You may even be able to get it under a former spouse's work record. A child can get Medicare under a parent's work record.

If you have an employer plan, it will pay first ("primary") for the first 30 months that you can get Medicare (whether or not you take it). Medicare will pay second during those 30 months if you have it. After 30 months, it switches. Medicare pays first, and your other plan pays second.

Medicare Part B covers dialysis. The most Medicare Part B will pay is 80% of Medicare's allowed charge for dialysis—at home or in a clinic—after you meet your annual Part B deductible. You do need a second plan to pay the rest. This might be health plan through work, TRICARE, a private health plan, Medigap, Indian Health Services, etc. If you have no health plan and have a very low income and few assets, you may be able to get Medicaid (state medical assistance) in your state.

You are only responsible for what Medicare says a procedure should be billed. Medicare pays a fee based on DRG's or what a service or equipment typically costs in an area. Once a provider accepts Medicare as a payor, the provid-

er can only charge what Medicare pays. The bill received may be for much more. If the provider tries to collect, just explain that they can only bill for what Medicare has approved. Some bills take months and months to sort all that Medicare will pay because providers keep trying to bill them for more items. This is especially true for ESRD because it is very complicated and has lots of charges associated. ESRD patients are also very lucrative for providers. Not to worry, most all charges will be paid without any money from the patient.

Medicare Part A is free for ESRD patients and covers all hospital costs and transplant medications for three years post-transplant.

Medicare Part B costs about $105 per month and covers 80% of outpatient costs. Medicare also pays for 80% of dialysis treatments

Medicare Supplements or Medigap costs from $150 to $400 per month, but most ESRD patients won't qualify as they can reject those patients. The Supplements cover all charges not covered by Medicare. You have to be on Medicare first to qualify and some states require the age of 65 before you can get the policy. Also, if you don't have a Medigap policy in force for the first 12 months on Medicare, Medigap policies can deny coverage. Basically, they don't want to cover people with End Stage Renal Disease.

Medicare Part D is a supplement for medications. Humana at Walmart costs around $15.00 a month but none of them cover transplant medications. Other medications are needed for ESRD patients that are covered.

Medicaid

Medicaid is a state-based program that may pay for medical care for indigent, uninsured, and high dollar medical patients. Medicaid coverage is based on income. Then a spend-down amount for medical services, medications, devices etc is deducted from the income. If there is a hospitalization in a month that is $10,000 for example, most patients would qualify for that being paid. Application for Medicaid must be started within the month of treatment. Most hospitals have social workers who get the paperwork started right away if an admission occurs because they want to ensure the hospital is paid regardless.

If a patient applies for disability and be unable to work, then they automatically qualify for Medicare and Medicaid. Disability for ESRD by itself may be

difficult to qualify for if there are no other conditions.

If a patient has private insurance, then the first 30 months with the ESRD diagnosis, the private insurance pays for 80% and Medicare pays for 20%. After the first 30 months, Medicare becomes primary at 80% and private becomes secondary at 20%. Private insurance may pick up the co-pays for medicine. Here is a table to help determine qualification for Medical Coverage for End Stage Renal Disease when you are first diagnosed.

Working Year 1 without insurance
- Medicare Part A and $110 for Part B
- May qualify for Medicaid on spenddown basis in months of large bills
- Medications on dialysis and transplant (forever) and anti-rejection covered by Medicare (3 years)

Working Year 1 with private insurance
- 80% by Private insurance and 20% by Medicare with Part A free and $100 for Part B
- Medications may be covered by Private Insurance.

Working After 30 months without insurance
- Medicare Part A and $110 for Part B
- May qualify for Medicaid on spenddown basis in months of large bills
- Medications on dialysis and transplant (forever) and anti-rejection covered by Medicare (3 years).

Working After 30 months with private insurance
- 20% by Private insurance and 80% by Medicare with Part A free and $100 for Part B
- Medications on dialysis and transplant (forever) and anti-rejection covered by Medicare (3 years).

Not working - no insurance
- Medicare Part A and B, Medicaid free
- Medicaid
- Medications covered

Not working - on disability
- Medicare Part A and B, Medicaid free
- Medicaid
- Medications covered

One of the first decisions to make after kidney function has failed is to select the type of dialysis to use. This decision is rarely made financially but will be made by advice from your Renal physician.

End Stage Renal Disease patients are in a special category in Medicare, regardless of age and work history. Part A coverage (hospitalization) is free or covered and Part B is the same as for retirees, currently around $105 per month (2016).

- https://www.medicare.gov/your-medicare-costs/part-b-costs/part-b-costs.html
- https://www.medicare.gov/your-medicare-costs/part-a-costs/part-a-costs.html

When does Medicare start?

www.homedialysis.org has a calculator for Medicare start date and reports the following tips:

Good question—and this can be very important for you. Timing is everything. If you do dialysis in a clinic, Medicare will not start to pay until the first day of your 4th month of dialysis. You will need to pay any bills your health plan does not cover. If you don't have a health plan, you could owe tens of thousands of dollars for those first three months.

But, if you start training for any home treatment (or self-care in a clinic) before the first day of your 4th month of dialysis, Medicare will start on day one. This can save you tens of thousands of dollars for dialysis and other health care that Medicare will cover.

For example, let's say you start dialysis on June 1. But, you don't start self-dialysis training until after September 1. Medicare will start on September 1. But, if you start home training any time before September 1, your Medicare can be backdated to June 1. If you had a hospital stay, access surgery, or other health care the month you start dialysis; those could be covered by Medicare Part A or Part B.

Use the Medicare Calculator at http://www.homedialysis.org/home-dialysis-basics/calculator to see when Medicare will start based on when you started training.

Many dialysis patients aren't able to continue working so they may have to go on Medicaid for the co-pays. If there is a large medical bill that exceeds the income of a working patient, they may qualify for Medicaid.

Hemodialysis

Hemodialysis requires treatment three times per week in an outpatient setting or five or more treatments in a home based facility. Machines are run by nurses to pump blood out of the body for 3-4 hours at a sitting. The environment is more like intensive care than chemotherapy, and it never stops until death or transplantation.

Hemodialysis is billed out at around $35,00 to $50,000 per month but through the mystery of medical financial rock and roll, Medicare reimburses around $3,200 per month which pays for 80% of the treatment, and state-based Medicaid programs pay for a percentage of the rest. There are IV's such as for Epogen that may cost $3,000 a month separate from the other treatments but Medicare reimburses them. There is always some charges left over, but most patients usually can't and don't pay it.

There's no question of the financial impact on care for kidney patients. New expenses include dialysis, medications, treatments, doctors appointments, travel to and from dialysis, special diet restrictions, and increased hospitalization.

If a patient is lucky enough to have insurance at the start of dialysis treatment, private insurance pays for the first thirty months, and Medicare is secondary. Then after 30 months, Medicare is primary, and private insurance is secondary. Many dialysis patients aren't able to continue working so they may have to go on Medicaid for the co-pays.

Peritoneal Dialysis

Peritoneal Dialysis charges are made in the mysterious land of a provider to Medicare and Medicaid, and the patient is largely bypassed. There are outpatient lab tests and other medical events that may occur.

Transplantation

Transplantation is big time surgery and the processes before and after aren't cheap either. The good news is that Medicare pays for ESRD ("End Stage

Renal Disease") transplantation for 93% of the renal population regardless of age.

The kidney transplant costs on average $260,000 in the first year. If a pancreas transplant is performed for diabetics, the cost goes up to $475,000. Before you go into sticker shock, there are organizations to help with funding, and since it is done in a hospital, Medicare Part A pays for the surgery.
www.transplants.org
http://www.transplantliving.org/before-the-transplant/financing-a-transplant/directory/
http://www.aakp.org/

Before the transplant, trips and lodging to the transplant center will be required for recipients (and for donors if available).

During transplant all costs are covered by Medicare Part A. If a patient has to stay in the city post-transplant, and there may be costs associated with lodging. Some centers have funds to reimburse for travel. Some centers such as Mayo Clinic in Rochester, MN have transplant houses for patients at nominal costs. There may be costs of Medications.

Medications

Post-transplant medications can cost up to $5,000 per month. Make sure you have a Medicare Part D Supplement in place (Sign up Nov. 15 - Dec. 15 annually). Medicare pays directly for anti-rejection medications for three years post-transplant. But there are other expensive medications such as Sensipar ($3,000+) per month that may be required. These medication costs may be covered by Medicaid spend down costs.

Over time, the transplant medications reduce in usage and cost. Some pharmaceutical and private funds will help with the costs.

The Kidney Patient community has lobbied for years to make the medications reimbursed for the life of the transplant, but so far it hasn't been extended.

What can Family and Friends Do?

- If a patient can't continue to work, the expenses of living have to be replaced. Ask if you can help with the financial challenge of not having an income.
- Make sure the patient is getting treatment and medications as their life depends on it.
- Some patients will think about withdrawing treatment and dying rather than put their family through the financial trauma.
- Make sure you tell them how much they mean to you.
- Make sure the patient does not run out of necessities such as food.
- There are some plans to pay for heating and cooling for dialysis patients. Make sure the patient gets help in these areas when needed.
- Encourage the patient that there is always a way through this challenge.

Dialysis - Hemodialysis

Challenge: Replacing kidney function when kidneys have failed.
The National Association of Kidney Patients (http://www.aakp.org/dialysis-information/) says:

"Dialysis is a type of renal replacement therapy which is used to provide an artificial replacement for lost kidney function due to renal failure. It is a life support treatment and does not treat any kidney diseases. Dialysis may be used for very sick patients who have suddenly lost their kidney function (acute renal failure) or for quite stable patients who have permanently lost their kidney function (end-stage renal failure)."

Once kidney function has reached the stage of End Stage Renal Disease, artificial means must be enacted and adhered to, or death will occur. The kidneys cleanse the body of toxins (too much potassium for example) and fluids. The kidneys also add important elements to the body such as causing bone marrow to generate erythropoietin which creates red blood cells.

Before dialysis, some blood abnormalities may show up. Urine output may be normal, but the cleansing effect won't function. Dialysis takes the place of a functioning kidney, but not totally. The kidney filtrates all the time while dialysis only happens periodically.

Dialysis can be done at home or in a dialysis center. A dialysis port must be placed either in an artery or in the abdomen to provide dialysis. In the early days, a port is placed on the chest and used until a permanent graft or fistula can be built on the arm to manage long-term dialysis.

Hemodialysis requires a special diet which is mentioned in another Chapter.

What can Friends and Family Do?

- Learn all about hemodialysis
- Be a sympathetic listener
- Help with day to day needs such as providing rides to dialysis
- Learn about the diet
- Visit in the hospital when events happen

The Access - Hemodialysis

The Challenge: Keeping the access from getting infected or clotting off.

When you go on dialysis (and even if you get a transplant, there will be times you have to be dialyzed), there needs to be an access or port to do

blood or dialysis exchanges. Your arms need to be protected from surgeries or too many IV's. And don't even think about getting a tattoo.

Hemodialysis in early stages:

In hemodialysis, the blood is pumped through a machine with every heartbeat for 3-4 hours three times a week if it is conducted in center. The Problem is a large vein/artery needs to be accessible close to the surface of your skin so an access can be inserted. The vascular access is literally a dialysis patient's life line and has to be preserved at all costs.

The vascular access allows a large volume of blood to be pumped fast from your body to a dialysis machine which filters the blood from materials that the kidney can no longer handle, and returning back into the body materials that the kidney once provided.

If you get the diagnosis that you need to be dialyzed soon, a port will be installed in your chest. This is a temporary measure so dialysis can be conducted within a day or two if necessary. There are times when another access collapses, and this requires the intervention of a port. The port is inserted in your chest in one tube and has two tubes hanging down with a blue and red tip. When you come out of the procedure, there will be a bandage on the top that needs to be kept sterile.

Sterile means no showers, no immersion baths, and no swimming while you have an access, or it will get infected. Your access is basically a blood vessel sticking out of your chest and needs to be treated with care and kept sterile. When you dialyze, the nurses or caregivers will have masks on when they change the bandage and clean the site. They will also clean the tips of the hanging tubes before and after hooking them up to a machine. Then after the dialysis treatment, they will reverse and insert heparin in the tubes to cause a clot to form, clean the tips, and put the tips back on. They will also change the bandage at the top with each treatment.

IMPORTANT: Ask for a spare set of the tips on the end of the tubes.

If one cracks or starts to leak, you have to get to an Emergency Room right away. Hold them up to let gravity help. But if you have your own tips, you can quickly replace one until you get to the dialysis center.

Even with all precautions, they may get infections. We finally just stopped doing any type of shower and only did sponge baths to stop the infections. Also, it helps to sleep in a loose t-shirt, so the tails don't flop around. These infections can turn into blood inflections which are hard to treat and can be deadly.

If one becomes infected, a doctor will pull it out, treat with antibiotics and immediately put another one in elsewhere. You have to have a functioning port so dialysis can be continuous.

Hemodialysis with an AV Fistula or an AV Graft.

If there is time to build a fistula or graft, that will be done surgically initially in your arm after studies have shown that you have adequate blood flow. A fistula is built from animal products and may last longer than a graft and have fewer clots. A graft is made of plastics. Both require from weeks to months to heal enough to use.

AV (Arteriovenous) Fistula

An AV fistula is a connection between an artery and vein and is placed by a vascular surgeon. It's usually placed in a forearm or upper arm. The fistula requires two to months to heal, and if it doesn't work, the surgery has to be repeated until one is place that works.

After it has healed, the nurse or provider inserts two needles into the fistula. One needle is to draw the blood to the machine, and the other is to draw the blood back into the body. It's a little like opening the gate in a dam.

AV (Arteriovenous) Graft

An AV graft is a looped plastic tube that connects a vein to an artery by a vascular surgeon. It may be ready to use in two to three weeks. The bandages and sutures must be handled by the vascular surgeon and will need to be handled during the timeline he/she requires.

The main thing from a caregiver perspective is the keep the arm clean and safe between dialysis.

IMPORTANT: Not Using the Access Arm

- Don't ever let blood draws happen from the access unless a dialysis nurse does it during treatment.
- If you are in the hospital, put up a large sign above the bed saying which arm can't be used.
- Don't let blood pressures be taken in that arm. And don't lift anything that will endanger the arm.

IMPORTANT: Check Daily for the Access

You need to check the access every day for a dialysis "Trill" feeling. By placing a finger on the access, you should get the dialysis beat. If it stops, contact your doctor right away.

ACCESS methods longer term

Both the AV fistula and AV graft will migrate up towards the top of the skin where placed. It will cause a large tube-like bumpy surface. You will be asked about that in many circumstances. Just explain that it's your lifeline.

If you are on dialysis longer term (and that is the hope), you may have several of both types of grafts. They will be placed in arms, legs and other places as they stop working. It's best to keep them flowing as long as possible in one place, but it's unlikely that one will last for many years. If so, count your blessings. If not, just go on and get used to the next graft insertion.

What can Family and Friends Do?

- Learn about accesses
- Watch for signs of infections
- Learn how to feel and listen to the "Trill."
- Raise the red flag if any problems exist. It has to be taken care of in the next day or so to continue dialysis.

In Center caregiving - The waiting room

Challenge: How to productively manage the time it takes for Hemodialysis

Hemodialysis at dialysis centers takes chunks of time out of both the patient and caregiver lives. Your entire life is punctuated by treatments and in some cases, hospitalizations. If you work, you have to face the feelings you will have by not being available for your loved one's treatments.

If you have the freedom, you may want to attend the dialysis treatments with your loved one. All dialysis centers have a waiting room for patients at shift change and for caregivers who drift in and out. You can't usually accompany patients into the treatment areas. Waiting rooms may have coffee and books to read. Most have a TV to watch. If treatment is very early in the morning, most of the people in the waiting room are very sleepy and not interested in talking. Some caregivers sleep in their cars.

Later in the day, the people perk up and talk and laugh and share. This is where you may pick up coping hints. And maybe you have a few to share. You will make friends who are traveling the same journey you are.

Finding things to do while you wait

- Take a class
- Maintain a local community garden
- Go the gym and swim
- Eat a meal
- Go shopping
- Walk around parks
- Visit people in senior retirement centers
- Attend local meetings
- Go to the library
- Find a place to use a computer
- Get car serviced
- Take a nap
- Read the newspaper
- and many more
- Do laundry in a laundry center
- Go to meetings
- Volunteer in local events

The point is you can't just sit for several hours. But it's important to be fairly close to the dialysis center in case an emergency occurs. One time my son came out disoriented and couldn't remember what had happened. I asked the

Doctor, who was there what was wrong. She said it was probably just a result of the dialysis treatment. But I knew better. He had never acted like that. If I hadn't been there, they would have sent him home with devastating results.

He had a brain bleed, we found out after taking him immediately to the ER. He was Air Transported to a center and treated within the three-hour window for strokes. Had I been out of range, he might have been permanently impaired. As it was, they got the bleed stopped, and after a few months of treatment, the clot disappeared.

TIP: Always keep a bag packed in the car with clothes and extra medications for both the caregiver and the loved one because you never know when you have to go rapidly to another place for an emergency.

The Staff

Nurses and Nurse Techs

You will come to admire and even love the dialysis nurses and techs. They provide the important care that keeps your loved ones alive. And the longer they work at it, the better they get. We purposely chose a dialysis center that had nurses with over ten years of experience. They are great dialysis nurses; they are great at training others. Low turnover is important in staffing although you don't have control. But you do have the choice of centers, depending upon the geographical area in which you live.

We found that centers with high turnover resulted in more infections and mistakes. Centers that have a stream of newbies are to be avoided. Too much turnover and too many newbies mean there is a problem with management in their ability to attract and retain employees.

Once we settled into a center (and we moved to a new area to do this), the infections ceased. The treatments became centered around my son, and not around the equipment or procedures in the dialysis center. The nurses proactively contact doctors and facilities to ensure continuous treatment.

This care, in large part, extended his life and health significantly. For this, I will always be grateful and love the nurses who provided it over the fifteen years we dialyzed, especially at DCI Dialysis in West Plains, Missouri.

The Doctors

You will have a Renal Physician, who gives the orders for dialysis. They usually come to the dialysis center once a month. Additionally, you will be going to their office once a month or every three months. We have been advantaged by having great Doctors starting from a Pediatric Nephrologist in Phoenix, Arizona, Dr. Mel Cohen, to his last Nephrologist, Dr. Susan Woody in Springfield, Missouri.

You will see them very often if you are in the hospital for an event relating to renal disease. There will also be surgeons who come from time to time when needed. The surgeons usually build accesses and fix problems. Some great ones remembered are Dr. Ben Vanderwerf and Dr. Paul Garvin as well as the fantastic doctors at Mayo Clinic in Rochester, Minnesota.

Dr. Garvin saved my son's life several times when he was able to make a new graft when all other centers in multiple states had given up.

Renal Dietician - The Diet

The Dietician visits every month while the patient dialyzes. Labs that have been drawn have been reviewed. My son's labs were excellent, so the Dietician just said: "Keep Up the Good Work."

We learned on our own and through the internet has to manage the Renal diet. We checked the salt and potassium content of food, mostly ate fresh foods avoiding canned goods, and selectively chose where to eat out. We especially avoided Campbell's canned soup since it has very high salt content. By keeping the labs good, we were able to eat a few things usually avoided. For example, we were able to have potatoes (baked) once a week and french fries rarely.

One tip that really helped was keeping down nausea after dialysis. When my son would come out of dialysis, he would be hungry and thirsty and his blood pressure would be low due to the treatments.

We learned to avoid any foods with grease or oil as it made him nauseous. We went to Subway and got a coke (which immediately brought his blood pressure back up and made him feel better) and a Subway Cold Cut Combo

with veggies and mayonnaise (which would make him fuller). We called this the Jamie Special at the local Subway.

We could not use transportation provided because he would get nauseous on the trip home if he didn't eat or drink something.

Social Worker

We didn't use the services of Social Workers very much. They were very helpful to many patients who needed help with their insurance. They helped us plan for dialysis trips, lining up dialysis out of town. But one time, when a social worker was a newbie, she scheduled us into a treatment at a VA Hospital on the East Coast. This raised a red flag for me, and I called out there. The VA had no record of the scheduled treatment, and they do not handle people who are not veterans. We had to cancel the trip and never got a satisfactory explanation of why this occurred.

Social workers also have access to programs to help with food and housing and other needs.

The Patients

The other patients we met stay in our heart and soul. We got help and tips from them and traded what we knew. My son would always talk to the new patients and tell them how to handle things. He would encourage them to hang in there, that it would get better.

The patients come to the center in complete shock and most eventually adapt to the treatment scenarios. Some give up. Some die. The population changes but become beloved by other patients.

Some patients are difficult and non-compliant (not showing up for dialysis) and are mean to their nurses. They usually get transferred out to other centers or die sooner rather than later. That is because it takes an entire team to make dialysis go successfully.

Precautions

A dialysis center is like being in a hospital in a specialty care wing. In fact, most hospitals have in-house dialysis centers. The treatment areas are sterile.

But the dialysis population is more fragile than most. And the patients have to come to dialysis whether they are sick or not. Some centers have an area that is isolated when patients have some illness that is transmittable. One side effect of dialysis is that they have fewer colds than others because the cleansing of blood takes some of the virus away.

IMPORTANT: As a caregiver, you can't go into the center if you have any infectious disease as you may transmit it to other patients.

Taking Medications

One of the most important activities a caregiver can do is to make sure your loved one has enough medications and make sure they take their medications on time. We chose pharmacies that had several dialysis and transplant patients because they were much more experienced at getting the medications correctly and on time. Bradford Pharmacy in West Plains, Missouri owned by my childhood friend, Jack Johnson, was especially good with dialysis patients.

You cannot run out of medications. And you can't allow your patient to skip medications. This will be a constant concern and sometimes a battle with your loved one. We used Medi-planners seven days in advance to stay on top of it. I would check the planner to make sure my son was taking his meds. I would also fill the Medi-planner for him. We also carried extra medications in the car in case we got stranded.

Financial Issues

Nobody at a dialysis center should hassle you about payment for treatments. Period. You may get bills and phone calls from the accounting department. But you are not to be disturbed about the payments when you show up for treatment.

Shift Selection

You may have two-day shifts and one night shift for three days a week to choose from. But dialysis will be on a Monday-Wednesday-Friday or Tuesday-Thursday-Saturday schedule. If you have something like a separate Doctor's appointment, you can go on another day but it has to be scheduled in advance.

We always liked the early morning schedule that started around 5:30 a.m. The mid-day shifts starting around 10:00 just took the whole day away. Night schedules are good for those who work or go to school.

Some centers offer all night hemodialysis where you are hooked to a machine, and basically, you sleep all night. The staff is available to take care of problems.

Having a Job

Not a lot of dialysis patients have a job, but quite a few transplant patients can work. It depends on whether they have a job when they start down the slope of kidney disease. There are factors relating to work, and many studies have been done to determine the cause and come up with solutions.

One problem is scheduling work around dialysis schedules. If you dialyze early in the morning, starting at 5:00 a.m., you still won't be off the machine until 9:00 or 9:30 a.m. Your work may require you to be there earlier and don't understand why you have to be late two or three times a week. Night shifts may help this problem.

Travel is difficult and has to be arranged in other cities. This means finding a dialysis center and making sure you can get into the center when you need to.

Interviewing for a job has the same problems. You have restrictions in lifting with the arm with the access. When you leave dialysis, many days you don't feel well.

Some employers are afraid they may have to pay your medical expenses even when you explain that you are on Medicare and won't be in any company medical program.

Transportation

You have to have reliable transportation. Medicare does not provide transportation, but Medicaid does in most states. Public transportation may be an option. Caregivers can drive you to dialysis and pick you up. You can drive yourself, but there will be some days you don't feel like driving after dialysis. So drink some fluids and get back your equilibrium before you attempt to drive home.

Hobbies

Hobbies are very important to maintaining sanity and having fun. Some hobbies can be done in-center. My son Jamie always read comic books. Boxes and boxes of comic books. He felt the comics took him away to another universe.

Rest and relaxation

Most patients sleep while on dialysis but this isn't a good idea. The problem is if you go to sleep and your access arm is under covers, you could bleed to death if a port gets disconnected or from a mistake from the nurses or techs. They check on you very often, but you can slip into a coma and not be able to ask for help.

Also, you can have a precipitous drop in blood pressure. The nurses tell you to wave your hands and let them know but it can happen very rapidly. They give you more saline and tilt your dialysis chair backward to bring up your pressure. If you are asleep, this could happen, and neither of you would know. If it isn't stopped, you can go into shock and then into a coma.

What to expect

Patients who start dialysis are typically in a shock state when they start. They are scared and probably have not processed the fact they even have renal disease.

Sometimes, people feel worse in their first weeks or months of treatment before they start to feel better. Some patients feel better as excess fluids are taken off and perk right up.

But, you may never feel as good as you did before your kidneys failed without getting a transplant. Sometimes renal disease comes gradually, and the patient does not clearly know how bad they feel.

It will limit activities and time. It may limit the ability to hold a job or even keep a stable environment. There are programs to help with housing, heating, food, air conditioning, etc.

It may limit relationships with significant others and families. The added stress can be too much for some caregivers and friends. But we have been fortunate that my son fought to have relationships and keep friendships with all types of people for his entire life. He spent a lot of time (several hours a day at times) with his friend Dee Cates and her family which took him away for a while.

Skipping or Shortening Treatment

Skipping treatment should be avoided at all costs. If there is an ice storm coming or the roads are not able to be navigated, find a place to stay near the dialysis center. We had a major ice storm in the midwest in February 2009, so we stayed at a hotel within one block of the dialysis center. You should not go more than three days without treatment. When you miss a treatment, you put yourself at risk for long-term health effects including fluid overload, heart problems and permanent damage to your system.

Also, the meds given during dialysis such as Epogen needs to be given continuously as it impacts your ability to create red blood cells.

Patients get very tired of treatments and try to get the nurses to shorten their treatment, even if they don't feel well. But this can have long-term health effects as well. The amount of time to dialyze prescribed by your Physician is specifically to your disease and body type and needs to be completed. There are times when you have to come off early due to blood clots, machine malfunctions, or a blood pressure drops too fast. But give yourself the best chance of survival and do the dialysis.

Hope is what drives you to get a transplant or to get the next best treatment. We kept hope alive and went after and got four transplants.

Peritoneal Dialysis

Challenge: How to have dialysis without blood exchanges

We never were able to do this modality, so the information here is anecdotal and taken from the Internet. We did try by having surgery to implant a port, but the fluids could never go completely into his abdomen.

So, in the beginning, a rancher in Texas had no time for hemodialysis. His doctor invented a way for the abdominal wall to act as a kidney. The body is

fooled into exchanging toxins for needed additives. This requires moving large amounts of dialysate in and out of the abdominal lining.

This form of dialysis has fewer restrictions than hemodialysis including a more liberal diet, less time tied up to machines during the daytime, and less risk from the treatment itself.

The form of dialysis requires an abdominal lining that hasn't been penetrated, meaning with surgery or scar tissue. The dialysis solution needs to sit in the lining and not leak into the rest of the body.

The surgery to get started involves putting in a soft catheter into the abdomen. The standard catheter for PD is made of soft tubing for comfort. It has cuffs made of a polyester material, called Dacron; that merge with your scar tissue to keep it in place. The end of the tubing that is inside your abdomen has many holes to allow the free flow of solution in and out. After the catheter is placed, dialysis can be started almost immediately.

The good news is that the procedure does not require needle sticks. The better news is that it doesn't get infected as often and does not touch the blood or vascular system.

The best news is that it is done in a primarily home setting. The fluid fools your system into thinking that the abdomen is a kidney and releases the waste products and accepts the new fluid as normal.

Training is provided to allow you to handle the equipment. The site and the treatments must be protected and sterile. Any signs of infection must be reported to your Doctor.

Continuous Ambulatory Peritoneal Dialysis (CAPD)

The dialysate moves either by gravity, having bags of dialysate hanging on a pole and moving down through the abdomen and out a drain. This needs to be done four times per day. The dialysis solution stays in the abdomen until the next exchange. The waste material is drained before the dialysis begins and new dialysate is added.

Continuous Cycler-Assisted Peritoneal Dialysis (CCPD)

CCPD uses an automated cycler to perform three to five exchanges during the night while you sleep. In the morning, you begin one exchange with a dwell time that lasts the entire day.

The http://www.niddk.nih.gov/health-information/health-topics/kidney-disease/peritoneal-dialysis/Pages/facts.aspx web site says:

"If you've chosen CAPD, you may have a problem with the long overnight dwell time. It's normal for some of the dextrose in the solution to cross into your body and become glucose. The absorbed dextrose doesn't create a problem during short dwell times. But overnight, some people absorb so much dextrose that it starts to draw fluid from the peritoneal cavity back into the body, reducing the efficiency of the exchange. If you have this problem, you may be able to use a minicycler (a small version of a machine that automatically fills and drains your abdomen) to exchange your solution once or several times overnight while you sleep. These additional, shorter exchanges will minimize solution absorption and give you added clearance of wastes and excess fluid.

If you've chosen CCPD, you may have a solution absorption problem with the daytime exchange, which has a long dwell time. You may find you need an additional exchange in the mid-afternoon to increase the amount of waste removed and to prevent excessive absorption of solution."

What can Family Members or Friends Do?

- Make sure the patient has a safe and clean place to do their treatments
- Help with the management of supplies if asked

Peritoneal Dialysis access

The Challenge: Keeping an access clean

Even if you choose peritoneal dialysis, you may have to have hemodialysis done from time to time, so knowledge of both types of ports is necessary.

What Can Family and Friends Do?

- Learn all you can about managing the access.
- Be available to listen to any problems with the access.
- Look for signs of infections.

- Raise the red flag if any problems occur.

The Dialysis Diet

The Challenge: How to Overcome It

When you go on hemodialysis, you will be visited by a renal dietician with an extensive list of no-no foods. The first challenge is fluids. You will be advised only to drink two 8 ounce glasses total of all fluids. This can be very difficult, but it is dependent on if you still can urinate. Dialysis is the only way to remove fluid when you no longer have kidney function. Peritoneal dialysis patients do not have as many dietary or fluid restrictions, at least not the dangerous ones.

Fluid buildup

Fluid buildup between dialysis treatments can be dangerous. Too much fluid can cause symptoms of congestive heart failure and shortness of breath. My son Jamie would gain from 6 to 10 pounds between dialysis treatments. I once asked a dialysis nurse what was the most any patient had ever gained. She spoke of a patient that was a heavy drinker who binged and gained thirty-five pounds over a long weekend. It took three treatments to get him back to his dry weight. The goal is to gain as little as possible during treatment.

Dry Weight

The doctor and nurses will closely monitor what is called your dry weight which is the weight target during dialysis treatments. This weight changes as your body gains or loses weight. You need to have a scale and watch this weight closely to help determine what the optimum dry weight should be. Jamie was having trouble with swelling on one wrist and hand causing nerve pain. He went on a trip and dialyzed in a facility that took his dry weight a pound or two below his typical dry weight. The swelling and pain went away so when we got back home; we had the weight lowered. He could tell when he came off dialysis too heavy, and he would really be careful between treatments.

Fluids

Fluid restriction can be difficult, especially in summer. Dieticians recommend chewing on the ice when thirsty. They also recommended only two 8 ounce glasses of fluids daily. We found that Jamie could take in more fluids than that and still be okay. He learned to moderate his fluids.

On dialysis, fluids are removed fairly quickly over a 3-4 hours period which can cause patients to go into shock. If this happens, the nurse will tip the dialysis chair back and rapidly give them saline. So Jamie would feel very "wiped-out" after dialysis. Also, his blood pressure would also be very low after having fluids removed. We found that if he drank a coke directly after dialysis, it would stabilize his blood pressure. In fact, when we measured his blood pressure, the coke would bring his blood pressure up 10 to 20 points, and he would feel much better, ready to face the day instead of going to bed and sleeping all day.

Diet Restrictions

The most dangerous part of losing kidney function is that the body is unable to remove potassium and other toxic substances. Potassium has a relatively narrow range in which it isn't dangerous. Both low and high levels can cause heart failure. Blood tests are often given to determine potassium levels and are reviewed by nurses and dieticians. Peritoneal dialysis patients have far less dietary restrictions because they dialyze every day and toxins do not build up.

The potassium ranges are:
3.5 to 5.0 is safe
5.1 to 6.0 is the caution zone
6.0 and above is the danger zone

IMPORTANT: The physical signs of high potassium are weakness, numbness, and tingling.

The main thing is to avoid or limit high potassium foods. This is the first and most important ritual that a new dialysis patient needs to learn. Almost all foods have some potassium so smaller servings will create the limit. High potassium in food is above 200 milligrams of potassium per serving. A portion is considered to be one-half cup. Having a full cup can take the potassium up, so levels need to be watched.

Another important diet issue is salt or sodium. The more salt eaten, the more fluid is retained. Avoid all salt substitutes as potassium is used as a substitute. Read the sodium content and select foods less than 200 milligrams of salt.

What we did was learn to read the back packaging of foods to see how much potassium they have. Most canned foods have too much potassium and salt but can be drained and blanched if eaten in moderation. White bread and only white bread is what we ate, but most pasta is free of potassium.

One time we really wanted a pizza but worried about the tomato sauce. We learned over time to ask for a minimum amount of sauce for safety.

With fruits, fewer selections and smaller portions are better. Some canned fruits are okay if the juice is drained. With vegetables, salads of most varieties are safe. Once a week we would have a half of a baked potato. If we wanted potatoes in between, we would leach them and boil them a long time.

The fruits to high in potassium to avoid are:

Apricots	Avocado	Bananas
Cantelope	Dates	Dried fruits and figs
Grapefruit juice	Honeydew	Kiwi
Mango	Nectarine	Orange
Orange Juice	Papaya	Pomegranate
Prunes	Prune Juice	Raisins
	Watermelon	

Low-potassium fruits:

Apple	Apple juice	Applesauce
Apricots (canned in juice)	Blackberries	Blueberries
Cherries	Cranberries	Fruit Cocktail
Grapes	Grape Juice	Grapefruit
Mandarin oranges	Peaches	Pears
Pineapple	Pineapple juice	Plums
Raspberries	Strawberries	Tangerines

High Potassium Vegetables to avoid:

Acorn squash	Artichoke	Bamboo shoots
Baked beans	Butternut squash	Refried beans
Beets	Black beans	Broccoli
Brussels sprouts	Chinese cabbage	Carrots, raw
Dried beans and peas	Greens except kale	Hubbard squash
Kohlrabi	Lentils	Legumes
White mushrooms, cooked	Okra	Parsnips
Potatoes, white and sweet	Pumpkin	Rutabagas
Spinach	Tomatoes, tomato products	Vegetable juice

Vegetables low in Potassium:

Alfalfa Sprouts	Asparagus	Broccoli, raw or cooked
Cabbage, green and red	Carrots, cooked	Cauliflower
Celery	Corn	Cucumber
Eggplant	Kale	Lettuce
Mixed Vegetables	White mushrooms (raw)	Onions
Parsley	Peas, green	Peppers
Radish	Rhubarb	Water chestnuts
Watercress	Yellow squash	Zucchini squash

Some high-potassium vegetables can be eaten in moderation if they are leached or some of the potassium are removed. The leaching process is:

For Potatoes, Sweet Potatoes, Carrots, Beets, Winter Squash, and Rutabagas:

- Peel and place the vegetable in cold water so they won't darken.
- Slice vegetable 1/8 inch thick.
- Rinse in warm water for a few seconds.
- Soak for a minimum of two hours in warm water. Use ten times the amount of water to the amount of vegetables. If soaking longer, change the water every four hours.
- Rinse under warm water again for a few seconds.

- Cook vegetable with five times the amount of water to the amount of vegetable.

Other high potassium foods to avoid:

Bran and Bran products	Chocolate	Granola
Milk, all types	Molasses	Nutritional Supplements
Nuts and Seeds	Peanut Butter	Salt substitutes/Lite salt
Salt-free broth	Yogurt	Yogurt

Other low potassium foods:

Rice	Noodles	Pasta
Bread and bread products (not whole grains)	Cake, Angel or yellow	Coffee, limit to 8 ounces
Pies, without chocolate or high potassium fruits	Cookies without nuts or chocolate	Tea, limit to 16 ounces

The dialysis diet may seem overwhelming and restrictive. For example, proteins will be restricted. But patients get used to it after a few months. Once in awhile, they will have to have something that is restricted, but make those episodes few and far between.

Some patients get an overwhelming urge to drink water, so they should sip some water and eat some ice.

After dialysis, Jamie would feel "wiped out" due to the low blood pressure and low fluids. If he wasn't careful, he would get nauseous and spend several hours in bed.

We found a solution that worked for us. Right after dialysis, we would go to the local Subway and order a medium coke and a six-inch cold cut combo with lettuce, pickles, black olives and mayonnaise. This would raise his blood pressure and stop his nausea because he found that other fast foods with grease would not work. It would also allow him to function normally and not be wiped out for the rest of the day.

The subway got so used to us that they would start making his sandwich when we pulled into the parking area. Also, we were unusual in that we were ordering lunch at 10:00 a.m. rather than breakfast.

What Can Family and Friends Do?

- Learn the diet and make it part of your family meals.
- Learn the safe places to eat out (not too much sodium or potassium)
- Learn the signs and symptoms of high potassium
- Learn the signs and symptoms of congestive heart failure
- Know that you can go to any ER and any hospital and get dialysis treatments between regular dialysis sessions if you have a life-threatening situation
- Simplify food preparation and selections
- Avoid canned soups
- Read the backs of all food products, avoid high potassium, high salt

Choosing a Transplant Center and Team

Your nephrologist will refer you to a transplant center probably in your own state or near where you live. You need to do your own research to find the best transplant center for you. Because you have Medicare, which covers kidney transplants, your insurance is good at any transplant center. If you have Medicaid for co-pays, you usually can get coverage if a state touches your state.

The best transplant center is one that does a lot of transplants and has a high rate of recovery. The overall transplant rate is going up slowly.

The transplant registry for waiting lists is at http://www.srtr.org/csr/current/Centers/TransplantCenters.aspx?organcode=KI
which shows organs transplanted by hospital. If a hospital does very few transplants, stay away from it. The more transplants a hospital does, the better they get at it. For example, if the state of Oregon is selected, there are three centers, all of which do a fair number of transplants, including the Veterans Hospital.

A picture of the average time on a wait list for kidneys is shown at http://host.madison.com/news/local/health-med-fit/interactive-for-organ-transplants-access-differs-across-the-us/html_cc1c3111-d172-5178-bb78-d4a-ca3ccb575.html

For example, the wait list for the Nebraska Medical Center is only sixteen months. Wait lists for areas with smaller populations tend to be shorter. This is an average and may not apply if you are a hard to match candidate.

IMPORTANT: If you get turned down by one center try another. Don't give up.

Once you select one or more transplant centers, you get an appointment to determine if you are an acceptable recipient. The center will get your medical records and do an initial assessment. Then they will schedule tests locally and at their center. You will be interviewed by doctors, nurses, social workers, and nutritionists. They want to ensure you can handle a transplant and would be compliant once you get one. They may want you to quit smoking or lose weight. You need to do what they want as there are many other recipients who would be ahead of you in the selection.

The idea is to be a great candidate and work with the team. We have had great teams and bad teams. The great teams do comprehensive workups, communicate in a clear manner about the process, and follow through. One not so great team meandered around for four years and then finally rejected my son. The team at Mayo Clinic did the tests and told him the same week while we were there that he would cleared for transplant, the magic words.

Then every month you will give blood that is sent to the transplant center so it can be matched for a donor.

What can Family Members and Friends Do?

- Stay healthy and focused.
- Work with the transplant team

Encourage everybody you know to consider organ donation upon death. Have them put it on their driver's license, talk to their family (who has to approve), and let their wishes be known. The donor family may be in shock upon a death, so they need to decide before they have to decide.

Keep asking people to do living donations. You might get a match somehow and get your transplant sooner. Social Media like Facebook and outdoor advertising is creating opportunities for a stranger donation.

Understanding the Transplant List

Challenge: Getting a transplant from the transplant list

Getting listed for transplant:

- A transplant list (from UNOS the United Network for Organ Sharing) is for getting an organ from a deceased donor.
- You can get a kidney is from a living related or unrelated donor from friend or family
- Some new lists are called paired donation which matches you and your donor (if they do not match you) with another group of donors that might match. It creates a chain where a series of transplants occur at multiple center within a close date range.

Some kidney patients have conflict about getting a transplant or getting on the list. Some will defer getting on the list for ten years or more. We say, get on the list right away. There will always be a wait time, so let that time be ticking. Let the time you are deciding whether to do a transplant or not count towards the time on the list.

You can decide when the call comes for a transplant. You can turn it down and let the next person get the transplant. But you can't predict the status of your health as the years go by. You want to be in the best health you can be to accept a transplant.

Once you have been cleared for transplant by the transplant committee, you are listed on the national UNOS registry. Your place on the list is complicated and is dependent on your age (children get bumped up), you current health, your blood type, your location within each area, your antibodies, and other variables. If you are a child or have high antibodies (meaning your blood reacts to other blood and would reject a kidney), you will be higher on the list. The criteria are described in https://www.unos.org/. You can see calculators for the types of donations explained at: https://www.unos.org/transplantation/allocation-calculators/

Unos maintains the database for the matches but the Organ Procurement and Transplantation Network gets and delivers the kidneys. https://optn.transplant.hrsa.gov/learn/about-transplantation/transplant-process/ provides information about waiting times.

It's a very difficult waiting game. You pray. You cry. You hope. And many patients don't receive a transplant. That's why dialysis is so important. Other

organs like heart and lungs do not have a life-saving treatment like dialysis for backup. And you may need more than one transplant in your life.

Over time, you are bumped up the list. The longer you are on the waiting list, the higher you go. In our first transplant, with high antibodies, we waited two years, but my son Jamie was sixteen and on the children's list. The second wait was twelve years. He had finally reached the top of the list, but he still needed to have no rejecting antibodies and a high antigen match. He got a good match both times. The first from an 18-month-old donor and the second from a man in his fifties.

He was also tested for family donations and received a perfect match from his brother Michael and a partial match from me, his mother. The first kidney lasted eight years, and rejected do to a stent left in after surgery that was not removed. The second rejected when he caught Valley Fever and had to go off transplant meds. The third kidney rejected within three months. The fourth kidney lasted a year and was going strong, but my son died of an unrelated condition. I'd like to believe with all the medical advancement it would have lasted until he died of old age.

Your blood is taken periodically and sent to a cross-matching laboratory. The lab keeps historical blood, so if a potential donor comes it, it can be tested against all the blood you have given so a rejection can be ruled out as much as possible.

The testing tries to identify as close to a six-antigen match as possible, meaning a genealogical match. The University of California at Davis https://www.ucdmc.ucdavis.edu/transplant/learnabout/learn_hla_type_match.html explains this as:

Antigen Match

"Antigens are markers on the cells in your body, which help your body, tell the difference between self and non-self. This allows the body to protect itself by recognizing and attacking something that does not belong to it such as bacteria or viruses.

Your body also sees antigens on a transplanted organ that are different from its own, and it sends white blood cells to attack the organ. When your body

attacks the new organ, it is rejecting it. To help prevent rejection, you will take certain medicines called immunosuppressants.

Although there are many different antigens, there are six, which have been identified as having an important role in transplantation. They are the A, B, and DR antigens. There are two antigens for each letter, and they are identified by numbers. So, your HLA type might look something like this:
A2, A30
B8, B70
DR3, DR8
You inherit these from your parents, three (A, B, and DR) from your mother and three (A, B, and DR) from your father. Children born of the same parents may inherit the same combination or a different combination of antigens. If you have brothers or sisters, there is a 25% chance that you will have inherited the same six antigens as one of them, a 50% chance of having three of the same antigens and a 25% chance of having none of the same antigens. Except for identical twins and some brothers and sisters, it is very rare to get an exact match between two people, especially if they are unrelated. The chance of finding an exact match with an unrelated donor is about one in 100,000. Although we try to match antigens as much as possible for kidney and pancreas recipients, we do transplant organs into recipients who have no antigens in common, and these patients do very well. Some of them have never had a rejection episode. In other cases, we have seen patients who have had an exact six-antigen match have rejection occur because there are other antigens that have not yet been identified that may play a role in rejections. Unfortunately, there is no way of predicting who will experience rejection and it can occur at anytime."

My son Jamie had 99% antibodies, probably from blood transfusions he had received before they had treatment with EPO or the ability to build red blood cells. It means that only 1 % of the population would match him. The donor would need to be somebody who was very young or who had not had a lot of illnesses to counteract. A five antigen match was found once, but the test ruled it out.

At the time of transplant, they do a six hour crossmatch test to double check the probability of keeping the kidney. A crossmatch determines if your body already has antibodies formed against the donor's antigens. It is very important to know if you have antibodies against a possible donor, because if you are incompatible with that donor, you would not be safely receive a transplant. So, even at the last minute, a kidney could be given to another recipient.

Multiple Transplant Centers

You can get onto more than one transplant list by convincing a transplant center in another region to take your case. You have to be re-evaluated and be willing to travel a distance to be tested periodically and to get a transplant. If you recall from the news, Steve Jobs moved to the Memphis, Tennessee area to get a liver transplant. That's because the liver list was shorter there. His bet paid off. He got a transplant, not because he was Steve Jobs, but because he was on a shorter list.

After being turned down by Missouri transplant centers, we were accepted by Mayo Clinic in Rochester, Minnesota, which has a world-class transplant center. This put us on the list for Minnesota and northern states. Mayo accepts medically difficult, hard to match patients like my son Jamie. We eventually did receive two kidneys from Mayo, one from family and one from a deceased donor.

If you get sick, the transplant center needs to be notified to remove you temporarily from the list. If you get really sick, you may not be well enough to get a transplant. The underlying illness may contribute to rejection.

So the bottom line is to stay healthy, stay positive, and do whatever the transplant team says to do. And wait and hope and pray.

What can Family members and friends do?

- Hope, believe and pray
- Get tested to be a donor
- Help find a donor
- Mark your Driver's Liscense or register to be a donor upon death

Donating a kidney from a live donor

Sales people talk about the big ask. A marriage proposal is a big ask. Getting a loan is a big ask. But none is as big as asking a person for a kidney.

A living donor is an angel who is willing to undergo surgery, several weeks of recovery, and give you the gift of life. More people are stepping up. Some are from the increased awareness on Social Media. Facebook now has a place to record your wish to donate.

A living donor is either a family member, called living related donor, or a non-related living donor who comes from a friend, spouse, or stranger. Living donated kidneys provide better outcomes, and the kidneys tend to last longer. There are some altruistic donors who do not know their recipients.

Paired Donation

A living related donor can be a match or not. If not, there is an emerging system called paired donations where a donor and recipient join a chain of others and eventually there is a probability that each will find a match, depending on the participants in the chain. Then a series of transplants are done across the country. There are several paired donor networks listed at: http://www.kidneylink.org/PairedDonationOverview.aspx

An explanation of how the pairing works is: http://www.kidneylink.org/PairedDonationHowItWorks.aspx
They use a pairing algorithm that makes the best match of the pool.

There is also a kidney donor waiting list where a donor can give a kidney even though a paired match cannot be immediately found. Then after the surgery, the recipient gets bumped up the list to get a matched kidney.

There is a treatment for blood type incompatibilities which previously were unable to be matched. The recipient goes through a series of plasmapheresis injections to remove antibodies from the blood. This treatment can also be used for donations that appear to be rejectable. We went through this process as pioneer in the early days when I donated a kidney to my son. It didn't work for us because his antibodies were just too strong. But now, they have a lot of success with this process.

My son Michael gave my other son Jamie a living related donor that was a perfect match and lasted for four years. It rejected due to getting Valley Fever which caused my son to have to go off anti-rejection medications.

We were fortunate to have some people who tried to donate, but none was compatible.

When my Uncle Bud was near death at the age of 94, my Aunt Eva called and offered my son a kidney. She pointed out that he had always been in good

health. I knew he was too old to be a donor and verified it via the transplant center. But I loved her so much for trying. It meant she and other family members had prayed and thought about my son and how they could help.

The initial tests ruled our potential donors out. None made it all the way to the transplant center. But we met some people who did get these donations, and they are truly miracle givers.

The person donating must be in good health, not have any pre-existing conditions such as diabetes or cancer, and be in good mental health. They must be willing to take 2-6 weeks from work and life to make the donation. Their surgery and hospitalization are paid for but not their living expenses. You cannot compensate a donor per law, but you can contribute to their living expenses to travel to and receive a kidney. We met divorcees who donated.

In some countries, donors can be paid for the surgery. Some patients go offshore and get a kidney. It is my wish that the United States would pay donors a generous fee because it would increase the number of kidneys for donation.

The surgery to remove a kidney is called a nephrectomy. It can be done via a small number of incisions or a large incision that goes from the rib cage front to back. These are explained here: http://www.kidneylink.org/TypesofKidneyTransplants.aspx

I had the small incision type and my son Michael had the large incision. I was out of the hospital in a day and normally functioning in a week. He was in the hospital for two weeks and had a six week recovery. The safety of the operations roughly correlated to the safety of any surgery.

What Can Friends and Family Do?

- Talk to everybody online and in person.
- Put up a web site or posters.
- One enterprising young man delivered food to homeless people, passing out flyers for organ donation and got several potential donors.
- Give talks.
- Get involved in kidney organizations to increase donation.
- This is a big ask but ask anyway.
- Get local TV stations to show transplant stories.
- Share stories on Facebook and other Social Media sites.

- Answer questions about organ donation when asked.
- Lobby for kidney donors to be paid for donation.

What it's Like to Donate a Kidney

Challenge: Not enough kidneys for patients waiting for a transplant

When a renal patient qualifies for transplantation, they are placed on a national waiting list, called United Network for Organ Sharing ("UNOS") and a local transplant list per regions. The organs on these lists are from deceased donors. Because there is a shortage of organs, the wait may lengthy, and the kidney may never come. If the patient has high antibodies or is reactive to most other kidneys, the wait becomes even more complicated. A team of medical specialists and kidney patients work on the allocation criteria, and a centralized computer selects the donor and recipients. Kidneys are allocated based upon blood type, tissue match, the length of time on waiting list, immune status, the distance between potential recipient and donor, and degree of medical urgency. Children are given preference for some organs.

If a living related donor can be identified and qualified, the transplant surgery can take place when scheduled. The patient can then be released from dialysis treatments.

What does donating a kidney mean? Everything. It gives life back to kidney patients who are on dialysis and may slowly be going to the dance of death. It means life to those patients who have reasons that dialysis isn't working such as lack of a workable access port for hemodialysis or membrane dysfunction for a peritoneal dialysis patient. The donor is the caregiver. The recipient is the friend/loved one who no longer has kidneys that operate.

Your body has two kidneys, one is redundant. Each kidney on its own can provide 120% of what your body needs. Giving a kidney away has been shown not to impair your health.
See website: http://www.unos.org/donation/index.php?topic=living_donation

The kidney donation process involves extracting a kidney from a donor and placing it into a recipient on the same day. The kidney is extracted and evaluated before the recipient surgery can begin.

First, a prospective donor needs to pray and look inward to see if in their heart can make this choice. Then, they talk it over with loved ones to see if somebody may want to talk them out of it. They need to understand the risks and rewards of being an organ donor. A donor has to be old enough to understand the risks. In cases where the age or some other impairment exists, a guardian ad lidum may be appointed to help determine if a decision can be made.

My son Michael wanted to donate a kidney to Jamie since he was a child. His attitude was, "When he needs it, he's got it."

Since he was underage when Jamie needed a kidney, a guardian ad lidum was appointed so he had a voice outside the voice of the family. I was torn because the surgery involved both of my sons. The guardian determines if the donor is serious and not being influenced by other people.

The risks will be spelled out in great detail along the process. The reward for the donor is the best, most exciting, and most important gift ever to be given and will substantially change the recipient and give hope and a life extension.

Think about this. Nothing you will ever do besides giving birth or adopting will ever have as big an impact as this. It takes courage and hope and gives back the same.

Web sites that help make this decision are:
http://donatelife.net/
http://www.thenationalnetworkoforgandonors.org/
http://www.transplantliving.org/living-donation/

If you are serious, then a contact needs to be made to the transplant center handling the potential transplant. An alternative route is to contact a paired donation organization. Several organizations find donors and recipients and pair them with other donors and recipients enough times so that all recipients get the best donor. Do a Google search to find out about each one and to find out what the kidney centers think of the networks.

An evaluation of your health and the health of your organ will be conducted. Phone interviews and lab work done locally at your Doctor's office are

the first steps. The phone screening helps eliminate people with diseases and with psycho/social issues. The lab tests ensure that the body, at least today, is processing chemicals correctly. Your local doctor will submit a health history.

The next stage is to have a cross-match test which shows how well your kidney matches your friend or loved one. On the same day, you and your friend/loved one have labs drawn to send to the transplant center. The transplant center then looks at your tissue compatibility.

Your blood is mixed with your friend/loved one's blood. The resultant reaction is measured. They are looking for antigen matches between donor and recipient. There are six antigens currently measured which are inherited from your mother and father and their ancestors. A six antigen match is a perfect match and could be twins indicating a high probability of success. Each parent gives two antigens.

The match may not have to be perfect or a high number but if it looks good enough, then there may be blood treatments given to both donor and recipient to increase the compatibility.

If your blood is acceptable, then the next step is to do a complete health evaluation. Even if you get turned down along the way, you both will know you tried and your relationship will be forever strengthened by this attempt.

The health evaluation will be made at the transplant center. There are restrictions on monetary exchange for organ donation but helping with the travel is not one of them so the recipient family can help the donor with their expenses. See section on Financial Help. Chronic diseases such as diabetes, heart disease, lung disease, and a myriad of other conditions will eliminate you as a candidate.

The tests are done over several days and will require a multi-day trip to the transplant center unless it is local or within driving distance.

Besides the blood tests, there will be a 24-hour urine collection, heart tests which may include wearing a halter monitor for 24 hours, chest x-rays, kidney function tests where you drink large amounts of fluids and then scans are made of your bladder and kidney. There may be a colonoscopy required and mammograms for older women. So it's mostly fasting, drinking up, and getting rid of the urine. You will be given a psychological, sociological, and

nutritional evaluation. It will be the most comprehensive physical you will probably ever have. Once you have been certified as an organ donor, you can rest assured that you have good health.

Your friend/family member will also be evaluated to ensure they are healthy enough to withstand the surgery.

If all goes well, there will be a committee meeting by the transplant team involving the transplant surgeon, transplant nephrologist, case manager nurse, social worker, financial analyst (it's a big, expensive surgery) with reports from other specialists from test results. If they all agree, the transplant can be scheduled.

The schedule will be based on how long the recovery period will take, typically six weeks for donor and perhaps longer for recipient. It's unusual for the donor to need six weeks but they schedule it to be on the safe side, and it's probably a holdover from when the donor surgery was more extensive.

The surgery consists of two small incisions on the abdomen, right or left, depending on which kidney is to be removed. You go through general anesthesia and will be fasting beforehand.

The pre-operating atmosphere is a happy place, and both donor and recipient are awaiting last minute checkups by the transplant team. This surgery is about as good as it gets for all participants. You will both have on hospital garb and paraphernalia.

How long does it take?

An eternity for those in the waiting room. For the donor and recipient, you get knocked out by anesthesia and wake up in recovery with no concept of passing time. For the transplant team, a multi-hour intense period of time passing with no room for mistakes.

When the donor wakes up, there is an overwhelming need to find out how the recipient is doing and vice versa. When I gave my kidney to my son, I tried to call around the hospital but couldn't find out. I knew other family members would be told, so I finally talked to my son Michael who was called and reported things went well, and Jamie was in recovery. I plotted to

go see him. The nurses said no, not yet. Finally, I sneaked out in the middle of the night and went to ICU and saw him doing well. Then I could rest and recuperate.

The recuperation in the hospital is short if the small surgery is used, 2-3 days. You will need a caregiver for a week or two. Checkups on the surgical site will be done, and more blood tests. If all goes well, you will be released from the local area in a week or two to go home for the rest of getting well. If you are lucky, you will be the caregiver for the recipient as well.

You can see the miracle of the new kidney waking up and peeing and cleansing the blood. Lab tests get better. The recipient may need a few dialysis treatments to help the new kidney along. There may be IV treatments required to stop rejection. The recipient recovery may last from one to two months. The hospital stay is one to two weeks. Recovery at home involves weekly blood tests, then bi-weekly and monthly if all goes well. There is an entirely new regimen of medications to get used to.

Classes are conducted both before and after to manage the transplant. You learn to spot rejection signs and symptoms. If rejection symptoms occur, there are treatments to reverse rejection.

If a living donor kidney is rejected, both the donor and recipient will have stages of grief.

What can a Family Members or Friends do?

- Help find a donor
- Sign up to be tested for donation
- Support the donor as much as the recipient in their journey during hospitalization and afterwards

Donation of organs or the Gift of Life

Challenge: Should you donate your own or a family member's organs?

One way you can be an important and first person team member is to give the Gift of Life. That means donating organs from a family member who has died and met the criteria for donation. The conversation on donation needs to be done before death and should be a normal part of estate planning. Each person should decide if they want to donate their organs upon death

and tell their family about their choices. There is peace that comes from families when they know what to do. And knowing your family saved some lives brings even more peace and hope.

What do you need to know about Organ Donation?

There are 121, 442 people waiting for lifesaving organs according to www.unos.org, the national transplant listing and matching service. Unos ensures the ethical and fair distribution of organs.

You can sign up to be a donor at this site or have it placed on the back of your driver's license.

- You can be an organ donor at any age
- Donation can be done with many medical complications.
- After a transplant, the recipient has over 80% survival rate.
- After donation, all funeral rituals including open caskets can be done.
- All major religions approve of organ and tissue donations.
- There is no cost associated with being an organ or tissue donor.
- On average, 21 people die each day while waiting for an organ.

One deceased donor can save up to eight lives through organ donation and can save and enhance more than 100 lives through the lifesaving and healing gift of tissue donation.

A donor can specify which organs to use. Donations can be made for all organs including skin. I am donating skin to help with burn patients who need skin until they can grow their own. The cornea is the most commonly transplanted tissue. More than 40,000 corneal transplants take place each year in the United States.

But the big shortage is in the life-sustaining organs: heart, liver, kidney, pancreas, lungs, small intestines. Tissues include corneas, skin, veins, heart valves, tendons, ligaments, and bones. Some organs need to come from a donor who is brain dead but kept alive by machines. Extensive tests are done by doctors not associated with a transplant to determine that a donor cannot be revived.

The family will be approached at the hospital at a time when they are not prepared to deal with this decision. If they know in advance what their family member wanted to do, it makes the decision much easier. But in

many cases, they don't know. So the family is faced with a terrible but heroic choice. The more they know about organ donation, the better.

If they have met someone who has been saved by organ donation or if they have by chance encountered stories of heroes and recipients, they may be more inclined to donate.

If they decide to donate the organs, they will be given plenty of time to stay with their family member until the surgery starts to remove the organs.

These types of donations are the basis of hope for many recipients.

We are deeply and forever grateful to the donor families that gave a kidney to Jamie, twice. The first donor was a child eighteen months old. We met the donor family about two years after the transplant. They smiled and cried a little but overall, they were very happy their child's organs were giving life to other people like my son, Jamie. We never found out who the second donor was.

What can Friends and Family member do?

- Read and learn about Organ Donation
- Think and pray about it for yourself and your family before a death happens
- Make your and your family's preferences known by talking about it by signing donor cards.
- In the United States, the immediate family can override the preference of a loved one so make sure they don't.

Getting the Call for a transplant

There is no life event as exciting as getting the call from a transplant center saying they have a kidney for you. You go from zero to one hundred in less than a minute. The adrenaline kicks in, and you get so excited.

But be advised, not all calls result in a transplant. Sometimes last minute tests reveal the kidney to be incompatible and is given to another recipient. We were on day two of a vacation in Carmel, California when we got the call while my son was on dialysis. He had to be back to the center within six hours. We chartered a private plane to San Francisco where we caught a flight back to Phoenix. We stranded my mother and my other son Michael at our cabin, but they made their way home.

The kidney was not a good enough match, so we were turned down after going to the hospital for tests. We made the six-hour window, just. Later on, I heard there was something wrong with both kidneys, and they rejected. So, we were fortunate.

The first and last call we got for a kidney worked out. The first kidney came from a child eighteen months old who had been brain dead after drowning. The kidney was shipped in and placed in my son during the transplant surgery. The team explained that the kidney would grow to meet the needs of my sixteen-year-old son. And it did and lasted for eight years.

The kidney did not start functioning immediately, called a sleepy kidney, as it had been out of the donor for two days by the time it arrived. The transplant surgeon said it would wake up on day fourteen, and it did. Meanwhile, Jamie

had to go to dialysis, and we kept hoping and praying.

We met the donor family later and let them see where the kidney had been placed and was still pumping. We thanked them profusely for their donation.

The last kidney transplant called on a late Saturday afternoon when we were preparing to go to a fish fry for the Senior Citizens. The phone rang, and a Doctor said, "Hello, I'm Dr. X from Mayo Clinic."

I answered, "Oh, you have a kidney for us" because I knew we wouldn't get a call on a Saturday night.

He replied, "Yes. I think we do, but I must talk to James."

I replied, "Oh, he isn't here but here is his cell phone number."

I immediately went into action, throwing clean clothes in a hamper, not even bothering with a suitcase. I got his medications together and stuff we needed for a long car trip.

Meanwhile, Jamie's phone rang, and he answered. The Doctor told him he had a potential kidney. Jamie was so excited he dropped the phone. When he picked it up, the Doctor asked, "You want the kidney, don't you?"

Jamie said, "Yes I do." and headed home.

We called back asked if we need to take Air Evac but the center said it would be okay if we could make it in twelve hours, the time it took to drive from home to Mayo Clinic in Rochester, Minnesota.

When Jamie pulled up outside, I was in the middle of the road making him hurry to get started. I was laughing and crying and hoping.

We drove all night. I am not a night driver but with pit stops for coffee and bathroom breaks, we made it about 7:00 am.

They met us and rushed us to a room. You have never seen such a fast admission as when a transplant takes place. They took blood for a cross match. They did an assessment including looking over his entire body to make sure he didn't have a skin infection. His access had stopped functioning the day before, and he was scheduled for a re-build on Monday. So they put a port in

his chest, and he dialyzed one more time before the transplant and after the transplant.

We waited all day for the six-hour final cross-match. The surgeon who was scheduled to do his transplant dropped in and said he had to go to a meeting where he was speaking on the East Coast. He said we were in good hands with his backup as he had worked on Jamie before. But he was disappointed that he didn't get to participate.

When it was about seven o'clock p.m., I couldn't wait anymore and started out the door to ask the nurse if she had heard anything. Coming down the hall was the transplant team with a gurney smiling and laughing. They fetched Jamie and said the transplant is a GO!

The transplant surgeon looked at me and said, "You look like hell. Why don't you lay down in Jamie's bed and get some rest and I'll wake you up when we get through."

I did just that as they took him away. They came back about midnight, and I got into my cot and watched him all night. He was restless, but the kidney was already working as we could see the urine bag filling up. We heard later his original surgeon participated via speaker phone as the surgery took place.

He was in the hospital for about five days and then we stayed in town for a couple of weeks until tests showed the kidney was working. We had thrice weekly blood tests and then weekly and then monthly. While at the transplant house, we wore funny clothes because our packing was not optimal. We returned to the transplant center twice and things were looking good.

However, when the call comes and whatever the result, it will be one of the most important events in your life.

What Can Friends and Family Do?

- Always let the transplant center know where you are
- Always be available by cell phone for you and your family
- Keep a bag packed in your car trunk in case a call comes.
- Stay healthy. You don't want to miss out on a kidney because you are sick.

- Stay away from sick and infectious people
- Keep skin infections under control
- Be compliant with what the transplant center requires

Transplant Recipients - Antibodies

The Challenge: Finding kidneys that will work with a recipient

It is estimated that over 30 percent of the population waiting for a transplant is sensitized. Being sensitized means that there are harmful antibodies in the blood stream that would fight a transplanted organ. Individuals who have these antibodies have typically developed them through a previous exposure to foreign tissues that has been introduced through a blood transfusion, a previous transplant or pregnancy.

Many transplant recipients (up to 30%) have antibodies in the bloodstream that would react to a donor organ and cause it to reject. These antibodies come from blood transfusions, pregnancy or a previous transplant.

My son Jamie had very high antibodies of 99% which means his body would react to 99% of the donors that might be available. This made it almost impossible to get a kidney from anybody but a family member, but not quite. He received two perfect matches from the transplant list, one perfect match from his biological brother, and one transplant from me, his mother.

My kidney reacted to his body but not at a high level. So he went through a process called desensitization which removes some of the harmful antibodies from the blood stream and may allow a kidney to be transplanted.

The process is done through IVIg immunoglobulin drug from an IV alternated with plasmapheresis that exchanges plasma and also removes antibodies. After exchanges lasting over about six weeks, the tests showed it was a low level of sensitization. The transplant occurred.

But the kidney rejected over three months. The process was very early in its use, and his antibodies were too strong. But they've made a lot of progress since then. This process helps for paired and living related donations that don't quite match.

If you have very high antibodies like my son, you are put at the top of the transplant list in your region so if a kidney is donated that could work, they get first chance at the kidney.

My son waited twelve years for a kidney to match and it did work then.

What can a Family and Friends Do?

- Try to find organ donors
- Sign up to be a donor

Avoiding Infections

Challenge: Keeping Your Health from Being Compromised

The most common event to impair health is by infections. They may be viral with colds/flu, bacterial, or fungal.

Because you are in close medical situations so often by being in Doctor's clinics, going to dialysis and going to the hospital, you need to protect yourself as much as possible. By definition, you are going to be more fragile and susceptible to infections than the normal population.

And it doesn't matter how sick you are, you have to dialyze. I remember my son having a monster stomach flu where he was throwing up repeatedly, but he still had to be dialyzed. Some facilities have isolation areas for dialysis.

You may need to go the ER and be admitted to get dialysis at a hospital. As an End Stage Renal Disease patient on Medicare, you have the right to be admitted to any ER and get dialyzed.

In all cases, your nephrologist needs to be notified if you are sick.

Viral Infections

Viruses fly through the air and are taken in by touch and breathing. Avoidance of people who are sick is the most important prevention.

The primary prevention is hand washing, not getting close to sick people, and using a disposable facemask to defend against exposure.

If you get a transplant, they test for viral infections you have in your system and may put you on anti-viral medications.

A fringe benefit of hemodialysis is that the cleansing of the blood has a tendency to get rid of viral infections. We noticed that any cold or flu symptoms that my son had ceased after hemodialysis treatments.

And try to avoid spreading any viral infection to other patients on dialysis. When I would get sick, I would drive my son to dialysis, but I would sit in the car and not go into the waiting room. I would even find another place to go to the bathroom while waiting and use a face mask when appropriate.

Bacterial Infections

Bacteria is ubiquitous and is particularly troubling for kidney patients. Beyond the typical places of skin breaks, it can be introduced by blood and fluid transmission.

The infection can occur in used equipment not being disinfected. Dialyzers can be re-used, and the cleaning and refurbishing can cause problems. The area around places for dialysis may have bacteria. An infection can occur from within the body.

Bacterial infections are treated with antibiotics. Because of dialysis, antibiotics that are stronger and used earlier than in typical populations. And to prevent a bacterial infections from turning septic, stronger treatment is necessary. Some antibiotics are dialyzed out so specialty treatments are started. It is not unusual to have an IV with vancomycin started immediately.

It's also not unusual to have to be admitted to the hospital for a bacterial infection. The main approach is to treat it heavily and quickly and get your health restored.

Fungal Infections

We found out about this the hard way. My son Jamie starting getting really sick, running a fever and coughing. We suspected pneumonia and took him to an Urgent Care facility. The doctor took an X-Ray of his lungs and came back and said, "You either have Valley Fever or Lung Cancer as there are spectacular nodules in your lungs."

With that bad news, we were immediately taken to the hospital for admission. After several days of testing, the diagnosis was Valley Fever or Coccidiomycosis.

The Valley Fever infection is typical in desert areas like in Arizona and near Bakersfield, California. The fever is in dust and is breathed. In Phoenix, most people are exposed due to the dusty winds and construction. In fact, travelers going through the Airports have also been at risk for exposure. Another form of fungal infections is Coccidiomycosis, which is transmitted by breathing and being around chickens.

The problem is for transplant patients who have suppressed immune systems. Catching Valley Fever is a major health setback. Immunosuppressant drugs must be stopped which may result in a rejection of the transplanted kidneys. Then a year long daily administration of Amphotericin B has to be done which means going to the hospital every day and getting an IV.

We took the daily IV treatments for about a year and overcame this. Later on, his kidney rejected probably due to the transplanted kidney degradation. The nodules were surrounded and stopped by the treatment, but the fungus lies dormant and can re-occur. This may cause a transplant center to reject a patient, but some transplant centers accept patients.

We had two transplants after the fungal infection ordeal, neither of which rejected due to the fungus.

What Can Friends and Family Do?

- Make sure you don't go around when you are sick with anything.
- Use a facemask when exposed in a medical setting
- Wash hands and keep clean
- Don't infect other dialysis patients
- For transplant patients, think twice about going to areas with Valley Fever.

Taking Medications

Challenge: Keeping and taking Medications

The medication regimen for a kidney patients are complicated and have to be adhered to. When you are on dialysis, there will be some medications that

you take several times a day. When you have a transplant, the risks and odds of skipping medications increase exponentially and may result in the loss of a kidney.

It's like having a tsunami offshore waiting to wipe out all your efforts.

The first challenge is to find a pharmacy that can handle medications for kidney patients. We have found those nearest the dialysis centers were the best because they had the most patients. For transplant medications, some pharmacies do not stock or provide anti-rejection medications because they are so expensive and the population is so small.

Filling prescriptions is a pharmacy challenge because while the medications are paid for by Medicare/Medicaid, they may re-send requests back and forth to the provider to get them paid. Pharmacies are willing to give a few pills in case the approval hasn't come in.

Whatever happens, don't run out of medications, EVER. The last resort is to go to an ER and get the hospital pharmacy to treat with their medications.

We found that having a medi-planner with a week's worth of medications worked for us. We had to have seven days out because the pharmacies may not have the medications on hand. There are too many pills and too many times they must be taken just to take them out of bottles and may result in running out or missing medications.

It also makes it easy to grab a mediplanner in case of a trip away from home for a short time. Longer than the filled spots in the mediplanner requires taking medication bottles along.

What Can Friends and Families Do?

- Ask often and repeatedly, "Did you take your Meds?"
- Make sure they are getting their prescriptions filled. Offer to take them to the pharmacy or pick up medications for them.
- If, for any reason they can't get the medications paid for, pay for the meds for them. I have paid for meds for a transplant patient who could not get approved and was reimbursed later by the pharmacy.

Conditions Related to Kidney Failure and Their Treatments

The Challenge: Avoiding other diseases

This information is from http://www.niddk.nih.gov/health-information/health-topics/kidney-disease/peritoneal-dialysis/Pages/facts.aspx

"Your kidneys do much more than remove wastes and extra fluid. They also make hormones and balance chemicals in your system. When your kidneys stop working, you may have problems with anemia and conditions that affect your bones, nerves, and skin. Some of the more common conditions caused by kidney failure are fatigue, bone problems, joint problems, itching, and restless legs.

Anemia and Erythropoietin (EPO)

Anemia is a condition in which the volume of red blood cells is low. Red blood cells carry oxygen to cells throughout the body. Without oxygen, cells can't use the energy from food, so someone with anemia may tire easily and look pale. Anemia can also contribute to heart problems.

Anemia is common in people with kidney disease because the kidneys produce the hormone erythropoietin (EPO), which stimulates the bone marrow to produce red blood cells. Diseased kidneys often don't make enough EPO, and so the bone marrow makes fewer red blood cells. EPO is available commercially and is commonly given to patients on dialysis.

More information about the causes of and treatments for anemia in kidney failure is provided in the NIDDK health topic, Anemia in Kidney Disease.

Renal Osteodystrophy

The term "renal" describes things related to the kidneys. Renal osteodystrophy, or bone disease of kidney failure, affects up to 90 percent of dialysis patients. It causes bones to become thin and weak or malformed and affects both children and adults. Symptoms can be seen in growing children with kidney disease even before they start dialysis. Older patients and women who have gone through menopause are at greater risk for this disease.

More information about the causes of this bone disease and its treatment in dialysis patients is provided in the NIDDK health topic, Chronic Kidney Disease-Mineral and Bone Disorder.

Itching (Pruritus)

Many people treated with peritoneal dialysis complain of itchy skin. Itching is common even in people who don't have kidney disease; with kidney failure, however, itching can be made worse by uremic toxins in the blood that dialysis doesn't adequately remove. The problem can also be related to high levels of parathyroid hormone (PTH). Some people have found dramatic relief after having their parathyroid glands removed. But a cure that works for everyone has not been found. Phosphate binders seem to help some people; others find relief after exposure to ultraviolet light. Still others improve with EPO shots. A few antihistamines (Benadryl, Atarax, Vistaril) have been found to help; also, capsaicin cream applied to the skin may relieve itching by deadening nerve impulses. In any case, taking care of dry skin is important. Applying creams with lanolin or camphor may help.

Sleep Disorders

Patients on dialysis often have insomnia, and some people have a specific problem called sleep apnea syndrome. Episodes of apnea are breaks in breathing during sleep. Over time, these sleep disturbances can lead to "day-night reversal" (insomnia at night, sleepiness during the day), headache, depression, and decreased alertness. The apnea may be related to the effects of advanced kidney failure on the control of breathing. Treatments that work with people who have sleep apnea, whether they have kidney failure or not, include losing weight, changing sleeping position, and wearing a mask that gently pumps air continuously into the nose, called nasal continuous positive airway pressure (CPAP). Many people on dialysis have trouble sleeping at night because of aching, uncomfortable, jittery, or restless legs. You may feel a strong impulse to kick or thrash your legs. Kicking may occur during sleep and disturb a bed partner throughout the night. Theories about the causes of this syndrome include nerve damage and chemical imbalances.

Moderate exercise during the day may help, but exercising a few hours before bedtime can make it worse. People with restless leg syndrome should reduce or avoid caffeine, alcohol, and tobacco; some people also find relief with mas-

sages or warm baths. A class of drugs called benzodiazepines, often used to treat insomnia or anxiety, may help as well. These prescription drugs include Klonopin, Librium, Valium, and Halcion. A newer and sometimes more effective therapy is levodopa (Sinemet), a drug used to treat Parkinson's disease.

Sleep disorders may seem unimportant, but they can impair your quality of life. Don't hesitate to raise these problems with your nurse, doctor, or social worker.

Amyloidosis

Dialysis-related amyloidosis (DRA) is common in people who have been on dialysis for more than five years. DRA develops when proteins in the blood deposit on joints and tendons, causing pain, stiffness, and fluid in the joints, as is the case with arthritis. Working kidneys filter out these proteins, but dialysis is not as effective. More information is provided in the NIDDK health topic, Amyloidosis, and Kidney Disease."

Life Disruption

This is probably the most important impact of kidney disease. The treatments and events have to come first in your life and can't be avoided.

We had to set up for special schooling when my son was young because of his health issues. Transportation becomes very important. When you want to travel, you have to plan at least two months in advance to allow for getting dialysis in another location or to have supplies shipped to your destination.

You have to keep your dwelling and life relatively free of infection,.

What Can Friends and Families Do?

- Learn the signs and symptoms of some of the impacts of kidney disease
- Help by being sympathetic but helping keep things normal.
- Make sure compliance occurs
- Avoid situations where infection might occur including colds and flu
- Each journey through illnesses require new treatments and care and need your help for navigation.
- Hope, dream and pray when setbacks occur

Medical Events

Challenge: Coping with Medical Events

Medical events or interventions are a way of life for a kidney patient. Dialysis and transplantation both have appointments and treatments, but other events occur.

For example, while on dialysis, you can start losing too much blood causing you to lose consciousness. You will probably be carted off in an ambulance so they can give you lifesaving care.

You access will clot off from time to time, and you will need to go in to get it de-clotted within a day or two. If they can't open it up, you will have to get a new access put in surgically. Your access may get an infection and may need to be surgically removed.

You will be treated aggressively for all illnesses and may be hospitalized for events that others can have outpatient. If you have other illnesses such as diabetes, you will be an even more frequent visitor. Kidney patients are hospitalized more often than they like. If you have congestive heart failure or other heart disease and kidney disease, you will increase hospital visits.

What Can You and Your Family Do?

- Your life will revolve around medical events. You have to learn to accept this and move on.
- Continue to enjoy and practice life events like holidays, birthdays, marriages, babies being born and other important rituals. Our friend, Violet Hegedis would say "I'm gonna make party." And what a party it would be. Joe would roast pigs and lambs and goats. Many of their extended family would show up. And they always included us as their family.
- Be there or call when hospitalization happens.

Rights and Responsibilities

The Challenge: Getting the respect you deserve

Rights

Every medical facility has a printed and wall displayed set of rights and responsibilities. It's good to get familiar with them if you need to lodge a complaint. Besides, it's something to read if you get bored.

As a Renal patient, you have a complicated journey through medical events. You are covered by laws that protect renal patients both in treatments and financially. It's one of the few diseases where you will be treated regardless of age, existing medical insurance, or other circumstances. You will be guided (including getting help to ensure transportation to treatments) and treated regardless of where you live. It goes without saying that you will be treated fairly regardless of race, sex, and pre-existing conditions.

So some big issues are taken off the table; mainly, how to get the treatments paid for and where you will be treated. You have a right to select where you will be treated within the United States and who will treat you. When you get diagnosed, you will have rights that other patients may not have.

It boils down to having the rights to be treated and be treated fairly and with the best acceptable practices at the time. One patient made a practice of dialyzing at different facilities in her area so she knew she had the best treatment.

You have the rights to all your medical records. Renal patients have critical access to lab values and other medical records. You can go to the medical records department of any facility and get copies (for which you may have to pay). This will be necessary when you change facilities or for other events. Some of the advanced centers provide all case notes, lab notes and events online viewable by you and your other medical providers. The electronic medical records movement is making positive differences in making treatments transparent and transportable.

You have the right to question any treatment and to understand what is happening to you. You have the right to complain and find out what happened

when a treatment went awry. You have the right to go up the organization chart for any problem that doesn't get resolved. Renal patients and providers are in a designated area in the United States, and each area had a council of advisors who deal with issues brought to them. The issue could be an untimely death or several unexpected deaths while on dialysis. They will investigate and learn why that is happening. There are standards for dialysis that are published on the www.medicare.gov site for dialysis providers and transplant outcomes.

There were two times where I assisted a patient who I thought was being treated unfairly. In one case, the dialysis facility tried to withhold treatment and kick him off dialysis. Luckily he got a transplant that weekend. The patient has the right to go to another facility if that happens. Another time a patient was treated poorly during treatment. I counselled the family to follow up and how to follow up.

You have the right to deny treatment after understanding the consequences of what that means. If you deny treatment when you kidneys have failed, you will die in a few days. So treatment denial is extremely important and needs to be thought through. This decision is entirely up to the patient, not the family.

Responsibilities

You are responsible for treating medical staff and facilities with respect and care. It's a two-way street.

It's important to be compliant, or the medical team may not be able to treat you with success. But this doesn't deny you the right to debate and have control over the treatment.

You have the responsibility to show up for treatment when scheduled, on time and prepared. In dialysis, if you don't show up for treatment, you may have to miss two more days if they can't fit you into the schedule and there are no more chairs.

You have the responsibility to make sure you wear appropriate and accessible clothes so dialysis can be performed. You have the responsibility to clean up and not smell if it can be avoided.

You have the responsibility to learn about your disease and do what you can to be well.

You have the responsibility to tell your medical team when something is going wrong or signs or symptoms that trouble you.

What Family and Friends Can Do?

- You can understand the rights and responsibilities of the patient
- Encourage patient to make use of the available information.
- Learn what is normal and abnormal and when the flags need to be raised on behalf of a patient.
- And stand behind the patient no matter what they want to do to rectify a situation.

Travel Financial Assistance for Transplantation

Challenge: How to pay to stay in town for transplantation

When you receive a transplant, you have to travel rapidly to the transplant center with no time to prepare for the stay. After you get out of the hospital, you will need to stay in town for a month and maybe several months.

Some large transplant centers such as Mayo Clinic have a transplant house which provides lodging for transplant recipients and families an affordable price. It was built because a volunteer for transplant patients determined that one of the problems was they couldn't afford to stay in hotels for them and their families until they were released. So they raised funds for a transplant center.

Don't let this get in your way. Most hospitals have a place for long-term stays at a discount. Get the transplant, and then deal with the other issues. If you are a child, the Ronald Mcdonald's houses are wondeful to stay in.

Several national non-profit organizations offer financial assistance for donors who are unable to afford the costs of travel. Many times these programs will also provide financial support for the donor to have a traveling companion.

Please speak with your Transplant Coordinator or Transplant Social Worker. They will be able to provide you with additional information.

Additional living donor assistance information can be found on the National Living Donor Assistance Center website at www.livingdonorassistance.org

What Can Friends and Family Do?

- Offer to take care of things at home while the patient is in the hospital.
- Raise or lend money for the lodging afterward.
- Call, visit, and write to patients while they recover.

Travel Tips for Outdoors

Challenge: Wanting to go Camping and Exploring

Kidney patients should not be kept from enjoying the outdoors, but some precautions are important. The selection of places to camp and explore are enormous in our great country. We have pitched tents in backyards and camping areas. We have rented cabins and motor homes to travel. We have gone boating and fishing. But my preference is still motels rather than camping out.

Some simple things to take for trips out in the boonies

- Aspirin - Take 1 to take down clots, reduces pain and swelling (Tylenol only does pain). Can be broken up and applied to bites
- A big bottle of Hydroperoxide for any wound cleaning, gum/teeth infections to gargle.
- Feel a sore throat coming on, stick your tongue way out 20 times. Kills bacteria that die on contact with oxygen. (Tip from an oral surgeon).
- Ace bandages in case leg swelling happens. Wrap from feet diagonally up the legs to the knees.
- Pacific Super Stoppers sterile sponge balls to stop wounds that bleed a lot or puncture wounds. Just hold it on and tape it down. Small 1 inch spheres.
- Sureseal Bandages - for wounds that bleed more than a couple of minutes. Like a band-aid. Gauze expands to cover wound. Small like a bandaid.
- Gloves and alcohol preps
- 2" by 2" non-woven sponges, four ply (not sterile)
- If legs start swelling, put a pillow when you sleep underneath the foot of the mattress and the swelling will go down as gravity works.
- Skin Glue can be used for simple, small wounds no more than 5 cm with straight edges.
- If a wound is large and can't be closed, it can heal from inside out by using wet to dry gauze and packing. See wet to dry wound techniques online.
- Take a simple flute and blow into it periodically. Helps lungs function better.

What can Friends and Family Do?

- Emergency calls must be available from just anywhere these days but you need to insure you can make a call, and that emergency people can get to your location.
- The next important issue is that they receive dialysis and not skip any treatments. That will limit the amount of time in the outdoors. Continuous Ambulatory Peritoneal Dialysis can be performed outdoors without electricity, but all other peritoneal dialysis needs electricity and some shelter.
- Another important issue is to take medications and any supplies needed for treatment. Always use sunscreen and insect repellent.
- Make sure your form of dialysis allows swimming as infections can seep into ports and catheters when swimming.
- And don't forget to have fun.

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